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your rights, your voice, your life

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Grounds for  
complaint

## East End boy

David Proud rolls into Albert Square

£2.80 Issue 22  
August 2009

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# editorial

## The erosion of Rights

How can it any longer be argued that our rights and the protection of them are not being abraded?

Where once we had bespoke anti-discrimination legislation we're now moving inexorably towards the increasingly leaky-looking single equalities umbrella. The Disability Discrimination Act was not by any stretch perfect. But it drew part of its strength from its very specificity, clearly defining disability as part of the rights agenda, having its own importance and its own set of issues.

What seems likely to replace it, as Caroline Gooding points out in this magazine, is something which lumps disability in with all other areas of potential discrimination and, either through neglect, bad drafting or by intent, significantly dilutes the responsibilities of local authorities not only to meet the needs and serve the rights of disabled people, but to show clearly and transparently that they are doing so.

When it comes to regulation, enforcement of rights and the prosecution of discriminators, how much more evidence is needed to prove that the Equality and Human Rights Commission

(EHRC) simply doesn't have either the teeth or the impetus for change that the former Disability Rights Commission (DRC) had. How many occasions for celebration have there been over the past 18 months following successful prosecutions brought by the EHRC on grounds of disability discrimination? Compare their record with the number of times victories in cases brought and supported by the DRC were reported in these pages.

**“We're now moving inexorably towards the increasingly leaky-looking single equalities umbrella”**

While, as disabled people, we need to stand alongside other groups who share our sense of disenfranchisement following the loss of powerful and effective rights commissions which lobbied in particular on race and gender issues, we all need to continue to dispute the sense of corralling us together under the aegis of an organisation which is so clearly not up to safeguarding our rights.

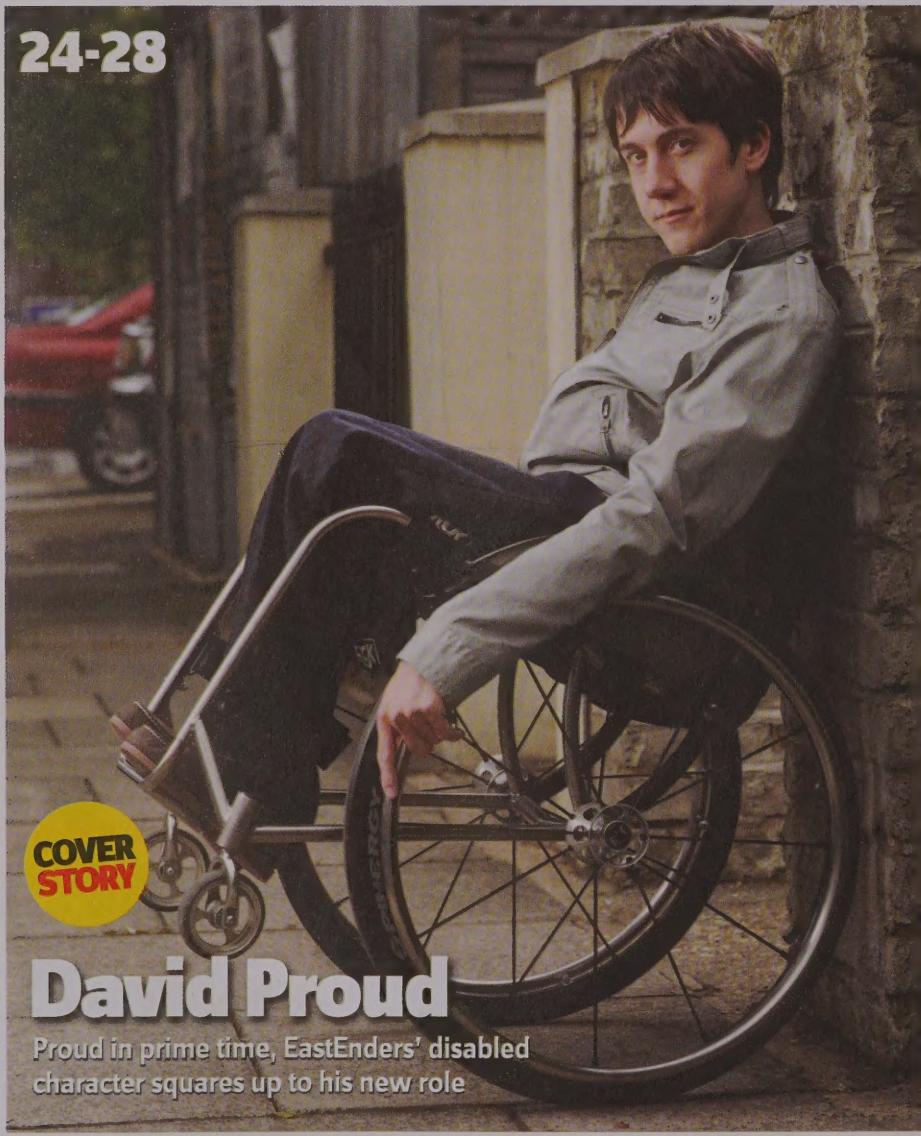


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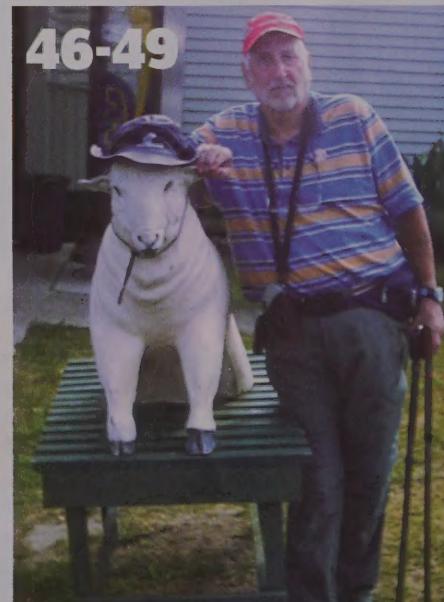


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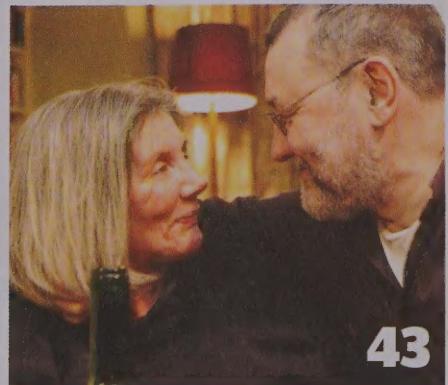
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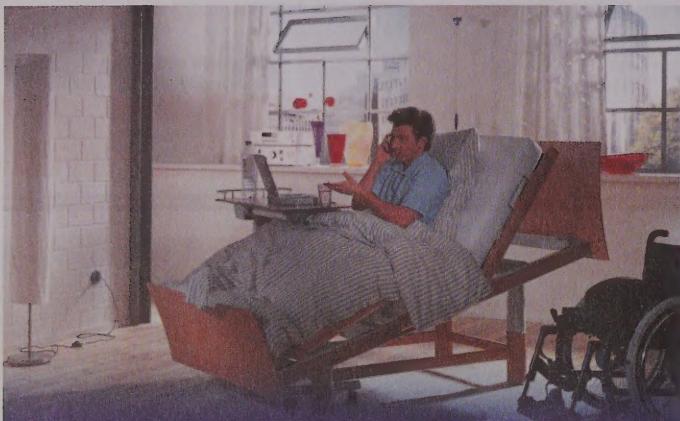
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# newsview

## Cooper no new broom on welfare reform

Although Yvette Cooper has only been Secretary of State for Work and Pensions for a short time, it is clear from our email exchange that she has no plans to revise the Government's strategy for shifting more disabled people off Incapacity Benefit and into work.

She talks about the strategy in the style that we have become accustomed to from her predecessor James Purnell and the Minister for Disabled People Jonathan Shaw.

So rather than talking about scroungers, she focuses on the importance of supporting more disabled people into work.

"We're undertaking the most radical reform of the welfare state for generations, and at its heart is making sure people are viewed as individuals, are listened to and supported in the right way for them."

She goes on to emphasise the importance of personal support to help disabled people overcome barriers to work. What's more, she insists that rising unemployment and a more competitive labour market strengthen the case for the Government's welfare reforms.

"When times are hard, it's more important than ever that we provide disabled



New Work And Pensions Secretary Yvette Cooper finds no reason to question the rhetoric or the agenda of the man she replaces, says **Sunil Peck**

people with the extra help they need. We must ensure no one is written off or consigned to a lifetime on benefits.

"But we must make sure there is proper support for those who can't work and that the system is sensitive to people's needs."

She brushes off concerns that disabled people could be forced into unsuitable jobs for fear of losing benefits.

"We've made it clear that

Flexible New Deal (FND) providers should tailor their support to people's needs. There are safeguards in place to prevent anyone in FND being required to take up a job that is not suitable."

But what about press reports that private companies with Pathways to Work contracts have been inflating the number of disabled people they have placed in employment in order to claim more government money? Don't these reports

discredit the strategy of using profit-driven companies to find work for disabled people?

Cooper ducks the question. Instead, she promises to clamp down on rogue companies. "Cases of fraud by providers or their staff are very rare. However, we take any such allegations extremely seriously and will take action where it happens."

"We will also recoup any money and involve the police if appropriate."

Our exchange yielded little about Cooper's previous experience of disabled people and disability. Instead she said: "One of my first opportunities as Work and Pensions Secretary was to attend the launch of the Right to Control national consultation. I was fortunate to meet and speak with disabled people who told me about the issues they face."

She went on to say that the Government had a duty to empower more disabled people with initiatives like Access to Work, the Job Introduction Scheme, Work Preparation and Workstep.

It seems there's still little to separate Labour and the Conservatives on welfare reform on Cooper's watch.

# newsupdate



REX FEATURES

## Users see red over green paper care blueprint

**Sunil Peck**

Campaigners have expressed disappointment that the Government's blueprint for a national care service overlooks thousands of disabled people.

Launching the *Shaping the Future of Care Together* green paper, health secretary Andy Burnham (pictured) said that everyone in England would have access to an equal standard of care regardless of where they lived or how much money they have.

The Government has ruled

out a general tax to fund the system on the basis that it would represent an unfair burden on working people. It has instead put forward three alternative funding options. A scheme where people fund their own care; an insurance scheme where people would be invited to pay into a state-backed fund to meet costs and a scheme where everyone who reached retirement age pays into a state insurance scheme regardless of whether they went on to need care.

Caroline Ellis, Joint Deputy Chief Executive of

Radar, welcomed the vision which includes a single assessment system.

But she questioned the amount of time it would take to overhaul the system because so many disabled people are already lacking social care support.

Peter Beresford, Chair of Shaping Our Lives, a national network of service users, said that the decision to rule out general tax was flawed because it assumed that all users of social care are older people.

"The Government talks about drawing up these

funding proposals after consulting with hundreds of service users but those sessions are where people have to come to them. We know that the people who most need social care are the ones who are least likely to do so."

Ian Loynes, Chief Executive of the Southampton Centre for Independent Living, welcomed the green paper but said that a wider debate on how social care support fitted into the independent living strategy was needed.

He also said that it was a "nonsense" to rule out general taxation along the lines of the health and education systems.

"I think it has always been the view of the disability movement that if we have to tax for this, the tax should be general and be across society recognising that everybody gains from including disabled people and enabling us to have a decent quality of life."

Meanwhile, Paul Corry, Director of Public Affairs at Rethink, said that the funding options for the national care service could be disastrous for people with mental health difficulties who would find it hard to fund contributions or who are discriminated against by insurance companies.

The consultation period runs until November.

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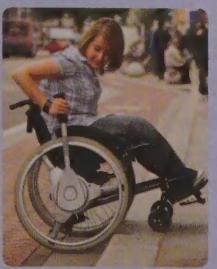
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# newsupdate

## Campbell swings Lords on assisted dying



ABI HARDWICK



ANDY RAIN / EPA

To die or not to die: Baroness Campbell (left) swung the Lords but Debbie Purdy (right) fights on

### Sunil Peck

An impassioned speech by a disabled peer in the House of Lords has thrown the issue of assisted dying into sharp relief.

In July, peers rejected an amendment to the coroners and justice bill proposed by Lord Falconer, which could have allowed people to help a disabled person to travel to a country to die without

the threat of prosecution.

Peers voted against the amendment by 194 votes to 141.

Baroness Campbell of Surbiton, the disabled peer who spoke against the amendment in the chamber, told *Disability Now* that she had heard conversations in the Lords and read articles in the press that assumed that the lives of disabled people who could not live

without the assistance of another human being must be intolerable. She said that such talk reflected "pretty scary times" for disabled people and wanted to secure the right for others like herself to gain more support and palliative care and live a dignified life.

"I'm not in favour of assisted dying while the culture is dominated by non-disabled people who feel

they'd rather be dead than live a life where they have difficulty breathing without assistance and people take them to the toilet. What I'm trying to do is take the mystery out of severe disability."

But Debbie Purdy, who has multiple sclerosis and is seeking legal clarification about whether her husband would face prosecution if he helped her travel abroad to die, said that she was "extremely disappointed" that the amendment had been defeated in the Lords.

She said that as the law stands, she will die early because she will need to travel to Switzerland while she is physically able to do so without needing her husband's assistance.

She told *Disability Now* that the issue of assisted dying boiled down to the individual's right to choose whether to live or die.

"I want my life to be as long and as happy as it can be. But when the pain and spasms outweigh the fun, I want to be able to choose to end my life and take the consequences. I don't want my husband to take them."

Debbie Purdy vowed to pursue all the options available to make sure that her husband could help her to die without endangering himself legally.





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# ruthpatrick

## Cameron's disability challenge

A dismal showing by Labour in the recent local and European elections suggests that the next British government will be Conservative. With less than a year at most before the next general election, **Ruth Patrick** turns her critical gaze to the right and considers what a Conservative Government might deliver for disabled people

**T**hose familiar with David Cameron's slick, new-look, Conservatives will be unsurprised to discover that where disability policy is concerned much gloss and rhetoric attempts to conceal a rather worrying lack of substance. Indeed, in researching this article the biggest challenge was to actually find any Conservative disability policies or proposals. Much of what is available is several years out of date and in the end I had to rely primarily on just one source: an article by the Shadow Minister for Disabled People, Mark Harper.

On welfare reform, the Conservatives are firmly tied to the "work is all" mantra and will continue Labour's obsession with getting disabled people out to work at all costs. Indeed, David Cameron, in a speech (admittedly from 2006) conflates work with disabled people behaving as responsible citizens, stating: "Disabled people need to take the responsibility of looking for work if they can, of taking their place in



David Cameron and Adrian Berrill-Cox, Conservative PPC for Islington North

society." One new Conservative twist though: Mark Harper suggests that more disabled people could be in work if the tide of economic migrants to Britain is firmly curtailed. Tying up disability issues with the politically sensitive issue of immigration seems both odd and wide off the mark.

Mark Harper also commits a future Conservative Government to simplifying disability benefits, critiquing the numerous different benefits available and the endless form filling this entails. Whilst this may be a correct analysis of the

problem, it is not clear what is being proposed as an alternative. Other Conservative policies include getting more disabled people into government as MPs and into Whitehall as civil servants and speeding up the roll-out of individual budgets nationally.

With an absence of detail and hard policies, it is difficult to predict what a future Conservative Government might mean for disabled

people. An early initiative of David Cameron's, the disability challenge website, has had no new entries since August 2008. This is rather ominous given that the site was billed as the Conservatives' tool for engaging and consulting with disabled people. When Mark Harper's office were challenged on this, they reported being "too busy" with parliamentary business to update the website, suggesting that when different priorities emerge, listening to disabled people themselves may easily fall off the agenda. It is vital that disabled people demand that the Conservatives do listen to their needs and aspirations and properly consult on new policies. With a new Conservative Government visible on the horizon, the time to start that dialogue is now.

- See [www.conervatives.com](http://www.conervatives.com) and [www.thedisabilitychallenge.com](http://www.thedisabilitychallenge.com) for more details

### → Have your say

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# politics

## No fuel payment means a long cold winter

The Government's refusal to extend Winter Fuel Payments to disabled people means another season of "eat or heat" choices, says **Paul Carter**



LEO WILKINSON PHOTOGRAPHY

**T**he Department for Work and Pensions (DWP) has insisted that it has no plans to extend Winter Fuel Payments to disabled people, despite a leading advisory body labelling the Government's approach to ending fuel poverty as "simply inadequate".

A new report by the Government's Fuel Poverty Advisory Group (FPAG) said that there are three times as many people in fuel poverty as five years ago, and that existing measures were not enough to deal with the scale of the problem.

Under the Government's own definition, a household is said to be in fuel poverty if ten per cent of its total

income is spent on fuel.

As previously reported in *Disability Now*, the Government admitted last year that almost 100,000 disabled people under the age of 60 are living in fuel poverty.

With average domestic fuel and energy prices having increased by 125 per cent over the past five years, it is likely that the number of households meeting the criteria is now even higher.

Chairman of FPAG, Derek Lickorish, said: "Unless fuel poverty is tackled head on, many hundreds of thousands more vulnerable pensioners, families and disabled people will struggle to afford their energy bills.

"A thorough strategy,

with decisive action on social tariffs and energy efficiency, is needed from the Government to help lift the poorest households out of fuel poverty."

However, a spokeswoman for the Department for Work and Pensions confirmed to *Disability Now* that despite the criticism from FPAG, there were still "no plans at this time to extend Winter Fuel Payments to people on higher rate Disability Living Allowance."

Jonathan Stearn, energy expert for Consumer Focus, urged the Government to

"heed the warning from its own advisory group" and move to protect disabled people before fuel poverty spirals out of control.

He said: "If the Government is serious in its aim to end fuel poverty, it needs to do much more to help the most vulnerable households.

"We need to see strong action within the upcoming Energy White Paper on energy efficiency measures for fuel poor homes, social tariffs and fair pricing to help the poorest customers to afford their bills."

The energy minister, David Kidney, defended the Government's record, saying it had spent more than £20 billion since 2000 on tackling fuel poverty.

"But we know the challenge needs further action and recognise that rising energy costs have reversed the downward trend on the number of households in fuel poverty.

"We will be doing all we can to ease the burden on low-income households and provide the support required to be able to heat and power their homes at an affordable cost."

### → Have your say

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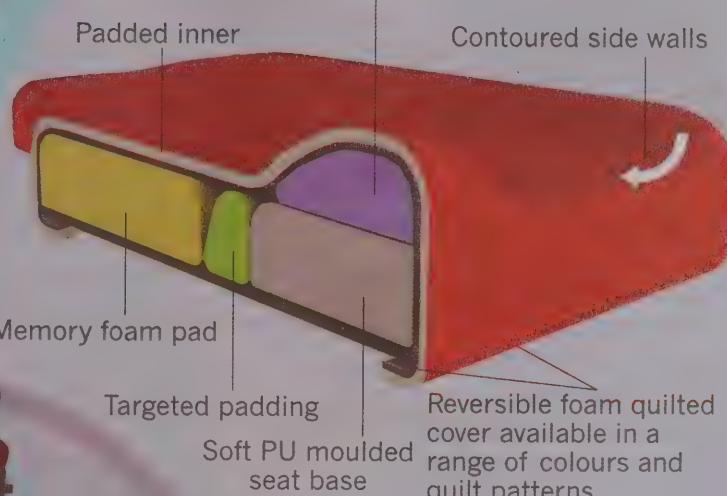
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# mediawatch

## We want what you've got

I've always had a rather down-to-earth view about why people need things, so I assume that disabled people will want access to stuff that other people have got access to, unless you can show me that they don't. If you think something's useful and good, then there's no reason I shouldn't have it.

People want access to television and to radio, and that's simply what I call "peer normative". So if you're 80, you're not necessarily going to be campaigning to make Facebook accessible to 80-year-olds, whereas TV and radio are peer normative.

The major barriers to full access are firstly that there isn't a legal right to it. So there's a regulated right of access to broadcasting in the UK but no regulated right on access to telecoms, and access to internet material is a bit up in the air.

Secondly, parts of the system are regulated so, for instance, in broadcasting, subtitling and audio description (AD) content is regulated by Ofcom but the design and usability of the sets that pick up AD and subtitles aren't regulated. So regulation isn't end to end and

Following the publication over the summer of several reports on access to digital content and equipment, Head of Access Consulting at AT Care and incoming chair of RNIB **Kevin Carey** (photo, below) looks at some of the issues



you end up with a situation like in the 1990s when, for a very long time, the BBC was required by the regulator to provide audio description and subtitles but there was no set-top box on the market that could decode the AD.

The reason the Government can't regulate hardware has to do with the R&TTE (Radiocommunications and Telecommunications Terminal Equipment) Directive from the European Union. The directive deregulated the design of hardware except in respect of health and

safety. So we can't actually regulate hardware unless we amend that directive.

If you look at the big issue for the last three years, it's been the switch-off of the analogue system. Now that wasn't driven by the market. That happened because the Government passed a law saying that after 2012, thou shalt not have analogue. So if the Government's going to use

a law to cut people off from analogue content, then it has an absolute duty to ensure that, at the very least, no citizen is worse off as a result.

You might argue that responsibility for access should devolve back to the manufacturers, but I think manufacturers have a duty to maximise shareholder return. The Government should override the market. They should legislate the means for making the digital signal and equipment accessible. They should calculate the difference between a normal set and making it accessible and then get a coalition together of its own funding, get more funding from the voluntary sector and maybe get the manufacturers to pitch in with a bit of their own money. That way, you get a partnership to fund the difference.

• Kevin Carey was talking to Ian Macrae

### → Have your say

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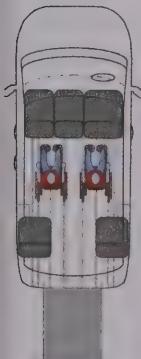
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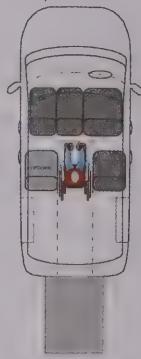
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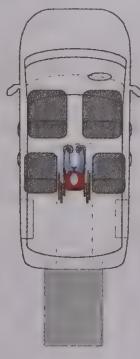
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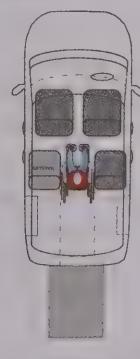
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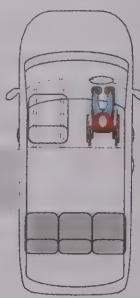
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# disabilityrights

## Unfit for purpose

As the Government's single equality bill continues its passage through Parliament, disability lawyer **Caroline Gooding** (pictured right) raises some concerns about what it's going to do for our rights

**T**he single equality bill was published on 27 April and aims to roll nine major pieces of legislation and some 100 statutory instruments into one single Act.

Among its measures, it will place a new equality duty on public bodies, replacing the three existing duties on gender, race and disability; require the use of public procurement to improve equality, protect carers from discrimination, ban discrimination in private clubs and strengthen protection from discrimination for disabled people.

These are worthy aims but I'm concerned with the way the bill is drafted. The bill could inadvertently weaken disability rights by failing to indicate clearly how they differ from other equality provisions.

For example, the law should specify that positive discrimination in favour of disabled people goes further than it does with other equality strands. That's not clear as the law is currently drafted.

Some employers advertise

opportunities exclusively for disabled applicants. It's legal for them to do so and it will still be legal after the bill is passed, but unless lawyers are absolutely clear about this, they may intervene wrongly to disallow it.

My second concern has to do with whether we'll be able to prevent a weakening of disability equality.

The bill fails to require public authorities to treat disability distinctively. It states that compliance may involve treating people "more favourably" but fails to reflect that disabled people's needs must be prioritised over other equality strands.

But my greatest concern is about the current consultation on the specific equality duties. At present authorities must produce equality schemes to show how they plan to promote disability alongside race and gender equality. The consultation proposes instead that authorities set equality objectives and draw up action plans for achieving these.

But how will an objective be defined? If there's a



requirement to set equality objectives but no stipulation on how many or how significant they must be, or that they should cover the whole range of the authorities' functions, authorities may be able to get away with doing very little.

The consultation also proposes that there should be no requirement to publish separate information about equality objectives or annual progress, but that these could instead be included in business plans. But how on earth could someone be expected to find equality policies in the lengthy business plans that public bodies produce? It makes a mockery of the goal of

greater transparency.

One improvement I think we can secure is a ban on all pre-employment questions about disability and health. This could really help stop employers discriminating in recruitment. The Government currently opposes this but a recent Work and Pensions Committee Report recommended it. Even the CBI supports it.

The equality bill isn't fit for purpose in its current form. But there's still time to change it and I'd urge disability groups to examine the proposals and send the Government their responses.

- Caroline Gooding is an honorary advisor to the charity RADAR

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# worldview

## Eynar's Nicaraguan world

Eynar Alexander Mendoza Vásquez's

life as a disabled person in  
Nicaragua



I'm currently a university student with few problems of discrimination given that the lecturers and students are understanding of my condition. But my path through education in Nicaragua has not always been smooth.

At four years old I started to walk. This was due not to any medical intervention; doctors I saw were discouraging and wrote me off. It was because of the belief and encouragement I had from my mother and grandmother.

I enrolled in pre-school at five. In the beginning, almost everything went well, until the day they did an activity that one of the teachers wouldn't allow me to take part in because of

my condition. My teacher even came and told me that I was a "spastic" who couldn't do anything. When I told my grandmother she immediately went to the school and told the headmistress that if she didn't dismiss the teacher she, my grandmother, would report her to the Ministry of Education.

That was my first step but not my last of course. Later, when I was six, I faced a greater trial: the world that surrounded me. On entering primary school I was now not only fighting to gain my teachers' and classmates' acceptance but the rest of society's too. At first sight they would make fun of me and call me names. Regarding education itself, I

had no more problems given that I was twice moved up in second and fourth grades for having excellent marks. I finished primary school as a good pupil.

But the beginning of each new stage was like starting all over again from scratch, since it was necessary to

**It's also hugely important that young people take part in any action carried out because change lies in our hands**

show I was capable of doing the same as the others. In the first two years of secondary school I sat in the classroom but didn't do the same;

because I couldn't write as fast as my classmates I just used to read the lesson. Even with this I carried on being a good pupil.

I continued my education in another school, the Rodolfo Rodríguez Alvarado Preventative School "Los Quinchos", where they welcomed me with the pleasure, respect and consideration that up until then only my family had shown me. I finished my secondary schooling there; it was the school where they treated me as just one more pupil and not as disabled and useless. There I learned that I wanted to be part of a more inclusive country.

Nowadays, the problem is physical access to the campus, due to lack of

alterations suitable for people with disabilities. Getting from my house to the university is a big problem because the buses aren't suitable for people with disabilities and most of the drivers aren't very understanding of my condition. Another barrier is adapting to the education programme.

Besides my studies I do other things such as voluntary work in my neighbourhood library, teaching children to play chess; I'm also part of a youth group that promotes environmental conservation and closeness to God, where we go on walks and meet up with other youth groups. Another interest of mine is playing football with my friends; I love it and really like the fact that I manage to play, even with the difficulty my motor condition presents, but what excites me most of all is the fact they let me join a team.

I also carry out voluntary work with ASNIC (the Nicaraguan Association for Inclusive Communities). ASNIC has given me an opportunity to carry out various activities in favour of disability, such as informing public universities about the need to adapt their entrance exams (for people with disabilities) and travelling to England in representation of the board of directors. The trip allowed me to see what



**Eynar Alexander Mendoza Vásquez**

policies could be applied in my country.

I believe we need to carry out a census which would show how many people with disabilities there are in Nicaragua, what they do and what opportunities, in every sense of the word, each one has. It's also hugely important that young people take part in any action carried out because change lies in our hands, implementing plans and strategies that will bring us change sooner. And, especially, young people with disabilities should take into account

that nobody will feel their pain, and that they are the most qualified in bringing about change in attitudes.

I think what is most lacking in Nicaragua is the willingness to help, given that in my personal case it wasn't resources that were of vital importance but the desire to help. By this I don't mean resources are unnecessary but without the desire to help or even the desire to do things, absolutely nothing would be possible. Without the existence of organisations to defend the rights of people with disabilities, nothing

would be achieved. The contribution of organisations such as ASNIC, Los Pipitos and ADIFIN (Nicaragua's disability organisation) amongst others has been to work on projects that raise the spirit of improvement and self-worth of children, young people and adults.

Currently, projects are underway to change the general public's views, in which people with disabilities teach awareness raising workshops in order to promote equal rights.

I want to finish by sharing with you what my family used to say to me when I was little; it's what showed me the path to becoming the person I am today – "Let's make an Eynar for the world and not a world for Eynar!"

Many thanks to the people who have given me the opportunity to express what a person with a disability feels, needs and deserves, which is to experience the inalienable rights of any human being.

• Written by Eynar Alexander Mendoza Vásquez, translation from the Spanish by Gill Holmes.  
 • ASNIC is a Nicaraguan development organisation supported by CODA International (a UK-based organisation that enables the participation of excluded groups in decision-making processes).

# onetowatch



## Genie's cosmic relaunch

Genie Cosmas is relaunching Stream Records, a label run by and for disabled artists. Her latest release, the stripped down jazzy Domestic Bliss is available to buy or download from [www.streamrecords.co.uk](http://www.streamrecords.co.uk). She answers our questions and tells us about her own domestic bliss and why Robert Wyatt is a hero

### What's the best thing about being disabled?

Decent access to gigs. I was on a platform recently with other disabled people and saw Neil Young at Hyde Park, which was better than being in the pit with everyone else.

### What makes you angry?

My husband: we argue about everything. He's a writer and I'm a musician. He's working class and I'm middle class and that class difference causes problems. He drives me crazy.

### What's the funniest thing anyone's ever said to you about your impairment?

People asking me if I'm drunk because of the way I walk, but I don't drink!

### If you were Prime Minister what one thing would you do to improve things for disabled people?

Make public transport and gig venues more accessible?

### What's the one thing that could be invented to make your life as a disabled person better?

A gadget to take the tops off all cans, jars and bottles.

### What do you most like about being a songwriter?

Expressing my emotions through music.

### And what do you not like about it?

It's very hard to progress in the music business.

### Who's your favourite disabled person ever?

Robert Wyatt. He played on one of my albums.

### Do you have any special or hidden talent?

An ability to make the best of every situation.

### How would you sum yourself up in ten words or less?

A feisty go-getter with a kind heart.

### → Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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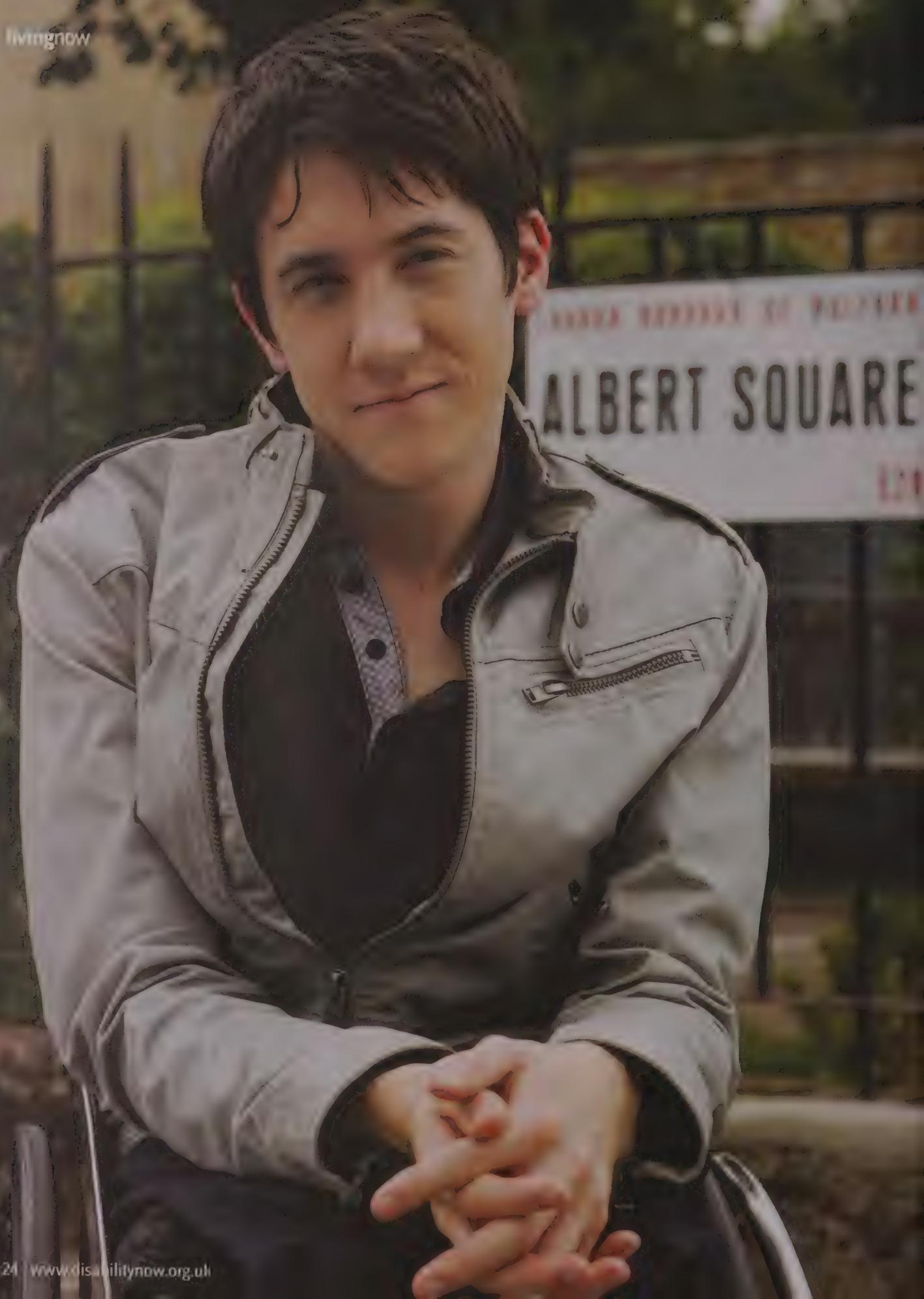
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# Pride of the Square

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**I**t seems quite surreal to call myself an actor." David Proud laughs a little nervously. We have caught the actor – sorry, we mean, regular working guy – in a break between filming scenes on the set of a very well known television soap.

David is the first disabled actor to be offered a permanent role in *EastEnders* since the inception of what is now the biggest British soap opera in 1985. A role that elevates him, if he wasn't already considered so, into professional actor territory. But he still isn't quite used to it. "It's weird when I'm approached in the street and people talk to me about being an actor because it's like I can't switch off from it," he says.

Born with spina bifida David has been in a wheelchair all his life, but that never stopped him when he was young from dreaming about being on stage. "The first part I ever wanted to play was Tiny Tim in the school play," he remembers. "I went up to the teacher and I said to her, 'I want to play Tiny Tim, I was born for the part!'

and from then onwards I had such a passion for drama."

That's when the determination to become an actor really started. David studied drama at GCSE level and then theatre at A Level, but he never realistically thought anything would come of it. "You look at TV shows and theatre and you just think 'it's never going to happen for me.'"

But then he saw an advert for an open audition for a BBC wheelchair basketball drama, and his life changed. "I had played wheelchair basketball and done some drama so I thought I was pretty average at both things! I went along to this massive sports hall full of people in wheelchairs and I kept getting invited back and the group kept getting smaller and smaller and my nerves built, then finally I was cast into one of the lead parts," David says, with a hint of accomplishment in his voice.

And rightly so. *Desperados*, which aired on CBBC in 2007, was a huge step forward for television for young adults, presenting a very normal image

of disabled people to its audience. David refers to it as a shining example that, logically, having an artist or actor in a wheelchair in a cast is not an impossible thing.

Though the Cambridgeshire-born actor was highly praised for his role in the drama, some of his friends and family were sceptical that he would be able to make a career out of what they called this "acting thing". Then he

**I went up to the teacher and I said to her, 'I want to play Tiny Tim, I was born for the part!'**

took his parents to a screening of *Desperados* in London and they saw how serious he was about it. "We had a meal afterwards and they said to me 'whatever you need to do to carry on acting, do it'. It was such a nice moment," he reflects.

That same night, David was introduced to a friend's agent; he took her for coffee and told her his dreams. ➔

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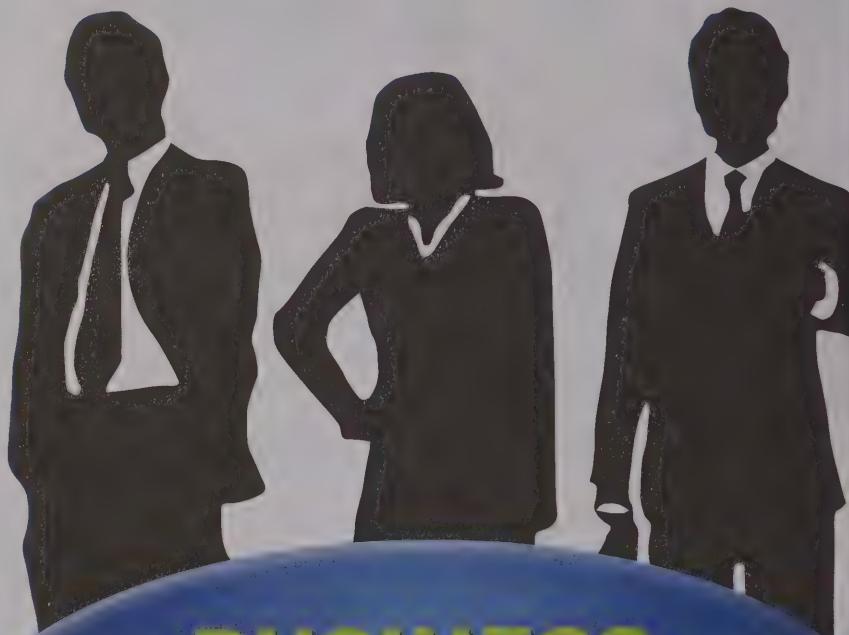
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BBC

David in character as Adam Best on the set of *EastEnders*

She later signed him onto her books and helped him get a bit part in the BBC drama *Secret Diary of a Call Girl*, and then a lead role in the feature film *Special People*.

"Special People" was such a family project, it only took 13 days to film but it has done so well at film festivals since and not just in the UK. The film has led to a lot of really nice moments of me seeing the world a bit and actually seeing what life for a disabled person might be like in a different country."

Asked whether he would like to do more films, David says: "Small British independent films are possibly the best thing you can do as an actor. I would definitely not say no, but right now I've got a lot of work ahead of me. Who knows where the future will go?"

The work David is referring to is, of course, his role in *EastEnders*, which

**We haven't tackled the height of the Queen Vic bar yet! But it's all representative, I mean, the world isn't accessible, and it's important that the set highlights this for my character**

he began shooting for last month. As an actor, getting cast in one of the biggest British television shows is a huge accomplishment. As a disabled person, getting cast in a permanent character role in one of the biggest British television shows is a breakthrough.

David is very quick to recognise this, gushing about how it is such a "wonderful opportunity" for the fifth time in 20 minutes. He adds: "I was wondering whether a regular part in something would come up and then

I got the call. It was spooky the way it all worked out."

In *EastEnders* David plays Adam Best, the son of character Manda Best, and a character described by a BBC press release as snobbish and self-centred. David doesn't agree. "The word I would use is 'spiky'", he says with a laugh. "He's lovely and refreshing, not a stereotype, a very unique character. There's lots of potential with him. He does ruffle feathers and stuff but I think the response [to him] is going to be good."

The cast and crew have been "wonderful" too, says David, at helping him fit in. "It can be quite manic at times, but comparatively [to my previous jobs] there are a lot of people here to support and look after you. Josie Lawrence, who plays my on-screen mum Manda, is lovely, she tells me off if I'm not eating well!"



Facing the access barriers of his new job isn't as daunting as David first anticipated either. "We haven't tackled the height of the Queen Vic bar yet!" he laughs. "But it's all representative, I mean, the world isn't accessible, and it's important that the set highlights this for my character."

David may not be the first actor to be cast in a permanent role in a British soap (this year already has seen Kelly-Marie Stewart appear in *Hollyoaks* and Kitty McGeever in *Emmerdale*), but the popularity of *EastEnders* and the power of the BBC arm will have a huge influence on the way media portrays and reacts to disabled people in the future. Hopefully it will mean that more disabled people are invited on-screen rather than being pushed behind the scenes. David is very



CLARE GROGAN

excited to be part of that change.

"To move representation of disability in the media forward is something I take a lot of pride in. It is one of those lovely bonuses of doing what I do, you feel like hopefully if you do it right you're encouraging more disabled people to get into acting and not just increasing people's

awareness of disability," he says.

David isn't worried about the inevitable narrow-mindedness of some of the *EastEnders* audience either. "Someone once said, 'If you can't laugh at yourself you're missing the joke of the century'. You will always get some people that disagree with the majority but I don't think it's their opinions that would matter to me."

It was two years ago now that David went for that coffee with his soon-to-be agent, in which he confessed his career ambitions. "I told her that my vision was to be a regular on a TV show in England..." he pauses.

"It's wonderful that I'm sat here today, just two years later, having already achieved that." ■

- David Proud will appear as Adam Best in *EastEnders* from November

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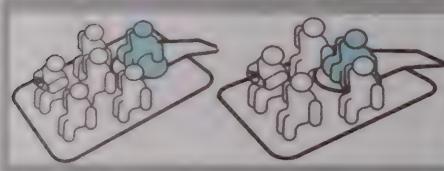
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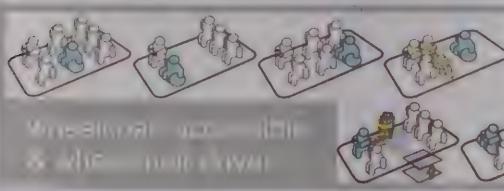
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# Football results

## Disabled fans on how grounds match up

With less than a month to go until the start of the new football season, chicken balti pies, flasks of Bovril and cold Tuesday nights in the snow will all soon be back on the agenda. However, as **Paul Carter** discovers, many disabled supporters still face problems in watching the beautiful game



CHAS BANKS/MUDSA

Chas Banks at Norwich City, showing an uncovered, and sloped pitch-side viewing area

**B**etween the months of August and May, hundreds of thousands of football fans pack up their flasks and scarves every weekend, travelling the length and breadth of the country in order to follow their beloved teams, and among those numbers of supporters are unsurprisingly many disabled people.

However, even for non-disabled people, going to the football can sometimes be as much of a stressful experience as it can be rewarding, exhilarating and exciting.

**When you're with your own fans there's an element of camaraderie, it's a bit more safe, you don't feel on edge, and you don't take any abuse!**

Large numbers of people, inhospitable toilets and unpredictable weather are all factors that can make life difficult for anyone. For disabled fans, these factors can be compounded.

At the majority of league grounds,

the only alternative to sitting in the stands with non-disabled supporters is to sit in a separate disabled supporters area, usually designed to accommodate wheelchair users.

Chas Banks is a committee member with Manchester United Disabled Supporters Association (MUDSA), who became disabled, and a wheelchair-user, in 1996, and says he had to find a new way to follow United.

"Before that, I didn't even know where the disabled people sat," he says.

He has strong views on the standard of facilities provided by some of the clubs, particularly when it comes to the viewing areas.

"There are some grounds that I refuse to go to on principle. I won't go to Portsmouth, because I think they're a disgrace, and I personally don't think they should be allowed in the Premier League. There are supposed to be minimum standards, and I don't think they should be allowed to play because their disabled facilities are so appalling. It's a nightmare if you're an away fan."

"Basically, you're at the opposite end of the ground. It's not just a different part, you're right at the far end of the ground and you're directly in line with the ball, at pitch level behind the goal. It's quite dangerous."

"You're also right in amongst their hardcore fans, it's pretty





**Left:** the narrow, retro-fitted platform at Arsenal; **right:** Aston Villa's covered, raised platform where fans can sit next to their PAs



horrendous really."

Paddy Cronesbury is chair of Middlesbrough FC Disabled Supporters Association (MDSA).

He agrees that having non-segregated platforms is far from ideal, and says he has witnessed first hand tensions between home supporters and disabled away fans in communal viewing areas, and in some cases even hostility between disabled fans themselves.

**Not all disabled people can just turn up at the ground and pay at the gate, you've got to work out how you're going to get in, in the first place**

"From a disabled point of view I think probably one of the downsides in quite a few cases, especially if you're a visiting fan, is that out of all the 92 league clubs, I think there's only about 34 that actually allow you to sit with your own fans, and that includes some of the big clubs as well who are 'culprits' if you like.

"At Liverpool for example, you're sat

behind the goal opposite the Kop End, surrounded by Liverpool fans. Your own fans are away to your right-hand side in the corner and you feel a bit detached.

"When you're with your own fans there's an element of camaraderie, it's a bit more safe, you don't feel on edge, and you don't take any abuse! Being in a wheelchair doesn't stop you getting abuse from away fans, it's a

level playing field in that sense."

Aside from the physical access problems, lack of advance information to access about facilities at different clubs can be a barrier.

Nick Saunders is disability liaison officer (DLO) for Exeter City FC, who play in League Two, English football's fourth tier. He is also chair of the club's DSA, so has experience of both



**Manchester United fans board the club's inclusive accessible coaches**



CHAS BANKS/MUDSA

**Left: Blackburn's below-level view obstructed by stewards; right: the view at Chelsea obstructed by stewards and substitutes**

sides of the coin.

"I always found that at away games, the difficult thing was finding the information to actually enable you to go to those games – which person to talk to to get the correct ticket information, parking information, stuff which a lot of disabled people actually need to find out if they do travel away."

"Not all disabled people can just turn up at the ground and pay at the gate, you've got to work out how you're going to get in, in the first place."

However, he says that as more and more clubs appoint their own dedicated DLOs, and the numbers of supporters' associations grow, information is becoming more readily available.

"Clubs having a DLO is a great thing, because it gives you a point of contact, and that's the biggest issue. If you haven't got a point of contact, it does make life a lot more difficult, because you just want to go to the game to enjoy it, you don't want the hassle of spending weeks trying to find out who you want to speak to. DLOs can be a great help to all disabled people."

Despite the obvious barriers that still exist, most disabled fans agree that

there have been huge strides to improve facilities in recent years, and to improve disabled people's awareness of their existence.

### **It's certainly not all doom and gloom, far, far from it**

The National Association of Disabled Supporters (NADS) is an organisation that represents disabled supporters of all sports, and campaigns for inclusion and equal access for all to sporting stadia. Its Level Playing Field campaign, which encourages clubs to promote their facilities for disabled people is now in its fourth year, and is backed by leading figures in the game such as former England internationals Trevor Brooking and Danny Wallace.

Chas Banks describes the facilities at Old Trafford now as "fantastic".

"It's just absolutely awesome, the experience as an away fan now," he says, although he says that the quality of facilities at other grounds "varies dramatically, depending on where you go."

He lists Aston Villa, Newcastle and West

Ham as being examples of good practice, while describing difficulty in seeing the action at Norwich and Blackburn.

Paddy Cronesbury says that many more clubs are now catching on to the idea that they need to provide raised viewing areas, that enable people to see even when those in front stand up.

"There have definitely been improvements," he says.

"There are more raised level options at some grounds whereas before it was a lifetime of sufferance where we were sat on the touchline and if you didn't like it, well tough, that was all you were going to get."

"It's certainly not all doom and gloom, far, far from it," says Nick.

"At some clubs, the improvements have been immense, even in the past four years. There's a hell of a difference, and I'm not just speaking as the DLO for Exeter City, I'm speaking generally for all disabled supporters because I get that feedback all the time through the DSA. A lot of clubs have improved drastically."

"Nothing is perfect though," says Paddy. "There's always room for improvement somewhere." ■

# yourviews

## The unemployment spiral

Regarding "Work and the Inclusion Illusion" (*Disability Now*, June 2009), my epilepsy is controlled with daily medication and I've been looking for a new, full-time, paid job for over seven years.

I feel that employers and employment agencies alike just don't wish to take me on, or that they're afraid to see me in work. I once had what I thought would be a

comfortable job with an engineering firm but they made me redundant in 2002 and I haven't been able to get myself a permanent role since then.

It's depressing. I've registered with many different agencies and I've called them repeatedly to ask about vacancies, only to be told "No" over and over again.

When I did get interviews I kept getting turned down

and when I asked why, it was always the same thing: I'm too experienced or I'm too highly qualified.

My feeling is that they only make these comments to avoid having to deal with my epilepsy.

Recently I started being told that my experience wasn't up to date, but that's not my fault: it's the product of the way I've been treated.

Firms turn a blind eye, or

### No exceptions

You're at it again, not letting facts get in the way of a good story ("Remploy's Bonus Bonanza Blasted", *Disability Now*, May 2009).

Why do we spend so much time and effort campaigning for mainstream education, employment and the right to run our own lives, and then, when the word "recession" comes round,

we start worrying about, oh dear, Remploy factories!?

Why should segregated workshops be more protected? I'm disabled, as are many of my colleagues, and we keep our jobs by making

a deaf ear, to disabled people like me and I'm appalled by it.

**Terry Stevens, by email**

### Just the odd job

I'd like to compile a list of disabled workmen because I think they'd be more trustworthy and do a better job for disabled customers than non-disabled workmen. Does anybody else think this is a good idea?

**Julianne Thompson, by telephone**

sure we give the market what it wants. From my perspective, the big six charities and Remploy factories have far too big a slice of the cake anyway. Were their resources given to user-led organisations and were Remploy encouraged to focus on supporting disabled people into mainstream employment rather than segregated workshops where disabled people remain cosseted for years, you'd have more disabled people in work at less cost and we'd all have far greater opportunity to manage our own affairs.

Come on, *Disability Now*: campaign for change, not for the status quo.

**Hugh Gunn, by email**





## 'Carer' claim concern

The article you ran on "carer" abuse ("Open to Abuse", *Disability Now*, July 2009) was actually about "care worker" abuse. I believe the term "carer" is enshrined in law as belonging to those of us who've taken on an unpaid caring role. In my own case, I've given up my nursing career to be a full-time carer and I found your article most distressing. I know there are many others on the Carers UK forum who feel as I do.

**Jane Sanders, by email**

### EDITOR'S RESPONSE

We didn't single out any particular group of people providing care in our piece, nor did we specify the nature of any relationship in any cases. Regardless of terminology (people who care are variously referred to as "carers", "care workers" and "personal assistants"), the 2009 study by University College London that Cathy Reay cited in her piece

found that over half of adults with dementia were mistreated by a family carer, through neglect, theft or physical or emotional abuse.

Your article "Open to Abuse" (*Disability Now*, July 2009) doesn't reflect the nature of the services that the Isle of Anglesey County Council provided to Miss Rylett. A full multi-agency investigation, including health officials, the police and social services, looked into the incidents to which you refer and no evidence of abuse was found. The care provided at the centre Miss Rylett referred to in the article has been praised by the vast majority of its users and their families. Our staff here on Anglesey are dedicated and take pride in offering a high quality level of care to our customers.

**T. Gwyn Jones, Acting Director of Social Services, Isle of Anglesey County Council**

## Cold blast of reality

I don't want to get political, and I agree that the subject of the winter fuel allowance has to be addressed by all political parties, but there's little that can be achieved when these parties are all convinced that the best way forward is for every disabled person to go out to work.

It's currently 26 degrees Celsius outside, I had to put my heating on this morning, and I'm writing this in a cardigan. It's the hottest day of the year so far but my direct debit for electricity and gas came to £108.00 last month. There's no difference between me (just turned 54) and a vulnerable pensioner except that they all, without exception, means test or scrutiny, get help with their heating costs regardless of their health, wealth or circumstances. The ex-speaker of the House, Michael Martin, receives £80,000 a year in pension, plus, guess what? – the winter fuel allowance.

Many pensioners aren't even in this country over the winter months, having chosen to spend it abroad, and yet they get the winter fuel allowance too. Some ex-UK residents who live in

warmer climes permanently are also entitled to it. As if he doesn't get enough, the ex-Chairman of the Royal Bank of Scotland has his pension topped up by it, as do the Queen and Prince Philip. The list goes on and on. Well, good for them.

I've written and spoken to MPs who agree that it's wrong in principle but don't think disabled people are unfairly treated because we've got the disability living allowance (DLA) to help us. Unfortunately in my case, there are no expenses to fiddle, no second home to go to, no jetting off to warmer climes. I just have to sit and shiver.

How many disabled people under 60 will die this winter because of fuel poverty and hypothermia? Officially none, because they're not included in government statistics. Pensioners can bring a government down, you see; disabled people apparently can't. It's a scandal.

DLA increases haven't even begun to match the spiralling cost of living, let alone the cost of being ill. We have to change the Government's views on this. **Anthony Smith, Duxford, Cambridge**

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## Britain's got disabled talent

As The Office for Disability Issues (ODI) is looking at how government can address negative attitudes towards disabled people, **Andy Rickell** has found a prime example of just such attitudes

I don't watch *Britain's Got Talent* or anything like it, but I have just watched Susan Boyle's first appearance on the show on YouTube because of what I heard happened. Her singing was magical but the audience reaction to her before she sang was anything but. The audience was laughing at her because they doubted that anyone with such a stereotypically unattractive appearance could have any facet worthy of notice. They were utterly shocked, as were the panel of Piers Morgan, Amanda Holden and Simon Cowell, that her talent vastly exceeded their expectations based on their judgment by appearances, and thankfully they were delighted for her.

This, though, exemplifies the battle that disabled people too often have to fight – the automatic presumption that disabled people are fundamentally incompetent and that therefore we are less valuable as human beings and not worthy of the resources and support to

achieve equality of opportunity. It is this deeply embedded public attitude that government must address.

### **The disabled person is assumed to be incapable of doing anything until we can prove otherwise**

In practice our attitudes about people work like this. A bit like Susan Boyle coming on to the stage, when we first see or meet people we make an initial assessment. If the person appears "normal" we assume they are capable of doing all the "normal" things, and only change our views if we find out there is something the person cannot do, and even then we usually assume they can still do everything else. If on the other hand the person is clearly impaired, the reverse applies. The disabled person is assumed to be incapable of doing anything until we can

prove otherwise (like Susan did with her singing), but even then we, as disabled people, are still assumed to be incapable of other things, until again we can prove our ability. This puts disabled people at enormous disadvantage, as well as being extremely pressurising for the individual disabled person who has to prove themselves at everything. It is entirely rational that some disabled people try to avoid disclosing their impairments – they just

### **If the person appears "normal" we assume they are capable of doing all the "normal" things, and only change our views if we find out there is something the person cannot do**

don't need the extra barriers and hassle it will instantly create.

This "presumption of incompetence" (as I call it) becomes a particularly big issue when people are about to make a judgment about a disabled person's competence that will have a major impact on our life chances – a work assessment, an application for an educational or training course, an interview for a job, a decision about life-enhancing medical intervention. To help those who judge us, we need to remind them of Susan. They need to allow us the support to get to the centre of the stage without making their minds up, and give us the space to demonstrate what we can do. It may be average, it may be spectacular, but it's us!

#### → **Have your say**

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# asktheexperts

you ask, they answer

## QUESTIONS AND ANSWERS

**Q**I need a DVD or some other training resource on communicating with people with communication disabilities. What can you recommend?  
**Paula Ellen**



**Agnes Fletcher says:** Some 2.5 million people in the UK have

language, speech and communication impairments (SLI). Sometimes this is as a result of conditions present at birth, such as a learning disability or cerebral palsy; sometimes impairments are diagnosed later, such as dyslexia or aphasia, or acquired later – as a result of a stroke, head injury or Parkinson's. For some people with SLI, the main challenge is the way that other people communicate and if they do so in an accessible and inclusive way. For others, augmentative and alternative commu-

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**What are Speech, Language and Communication Needs?**

What are speech, language and communication needs? | Why does it happen? | What is the effect? | Information for adults and children | Dictionary of terms in plain English

**Try to imagine...** being unable to read this being unable to tell someone else about it

**words coming out jumbled up** words getting stuck, someone jumping in, saying words for you

**not being able to understand, the signs and symbols around you** not understanding the words or phrases

**not being able to write down your ideas** people ignoring what you are trying to say; feeling embarrassed; and moving away...

**Back to top**

**What are speech, language and communication needs?**

nication (AAC) systems can enhance communication. AAC systems include eye pointing, signing, gesture, using symbol/word boards and electronic speech devices. Familiarity with the basics of these technologies can help interaction with people with SLI. But whether disabled or not, most of us could know more about this group of impairments and how we can

ensure that how we talk to people and how we provide information is as inclusive as possible. A useful place to start is [www.communicationsforum.org.uk](http://www.communicationsforum.org.uk). This site aims to promote awareness and knowledge of these impairments and to be the UK's main information resource for people with experience of them, their families and service

providers. The site includes:

- details of organisations that can help adults and children affected by SLI;
- information about speech and language therapy for adults and children;
- relevant news and events;
- scope for people to contribute to a dictionary of speech and language terms in plain English.

You can email the Communications Forum on [sscott@communicationsforum.org.uk](mailto:sscott@communicationsforum.org.uk) or phone 020 7378 3001. The site lists lots of specialist organisations that have the sort of resources you are looking for – too many to list here. To give a flavour, Afasic is a parent-led organisation set up to help children and young people with SLI and their families. It provides information and training for parents and professionals and produces a range of resources such as a CD and pack on *Including young*

## THE EXPERTS

We have experts who can answer questions in many areas that matter to us.

**Sexual & Personal issues:** **Simon Parritt**, a counselling psychologist who has studied psychosexual therapy, was the only disabled director of the

Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD).

### Legal Matters:

**Douglas Joy**, senior solicitor at the Disability Law Service, and his colleagues give advice on

disability and the law.

### Benefits and Debt issues:

**The Citizens Advice Bureau** puts its expertise at our disposal to help you.

### Technology and Internet:

**Léonie Watson** from digital consultancy Nomena is here to get you

connected and keep you up and running.

### Specialist or Adaptive Equipment:

**John Mandrak**, for nearly 25 years a disability journalist and consultant, gives advice on the Disabled Living Foundation's helpline.

people with speech and language impairments difficulties in secondary school; Is your school a communication-friendly school?, which has practical tips for staff in mainstream schools; and *Watch your language*, a resource for parents/carers of young people 11+ to share with youth and leisure services.

Other organisations offering resources that you can link to through the site are the Aidis Trust, which specialises in communications technologies, the British Dyslexia Association, the British Stammering Association, the Children's Brain Injury Trust, the Cued Speech Association, the Down's Syndrome Association, Communication Matters, the Dyspraxia Foundation, Headway (a Makaton site), the National Autistic Society, RNIB, RNID, Scope and Sense.

**Q** I want to travel to Uganda with my 19-year-old son, who

has cerebral palsy. We're seeing a consultant for correction of his spine in September. I've tried a few travel agents and none is willing to give me travel insurance as he's waiting for treatment. This has been going on for three years. Please let me know which companies would offer him travel insurance.

**Mrs Raja**



**Andy Wright says:** I suggest that you contact a company called Free Spirit on 0845 260 1578 and quote ref ACC2009 (Mon-Fri 8am – 6pm). It may give you a quote. It is a specialist insurance company used to insuring disabled travellers with a variety of pre-existing medical conditions and while it may be difficult because of the uncertainty of your son's situation, still awaiting confirmation and diagnosis etc, I think you have a better chance with this company than mainstream insurers.

**Q** We rent (from a housing association) one of two properties built for wheelchair users, because our daughter has cerebral palsy and uses a wheelchair. Both our neighbours were also wheelchair users, but the last person who lived there did a swap with a single parent with a 17-year-old fully able boy. The housing association says it couldn't stop this as it couldn't discriminate against a non-disabled person. I'm upset because I feel that letting somebody who isn't disabled live in a property built for wheelchair users discriminates against disabled people waiting on the housing list. I feel very strongly about this as we had to wait years for our property. Please advise.

**Michael Head**



**Kate Sheehan responds:**

Wheelchair

properties don't have to be let to households with wheelchair needs but a lot of housing associations have policies under the Disability Equality scheme to give preference to disabled people. But did the housing association know the mutual exchange was going ahead? If it did, did it know enough about its housing stock to realise that the property was specially designed? I suggest you ask it if it knew and, if it did, why it let this property go to a family with no need for adaptations. If you're not satisfied, ask to see its policy on lettings and the Disability Equality Duty and ask why it lets precious properties to people without disabilities when others are waiting.

#### → If you have a question for our panel

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**Travel:** Andy Wright is managing director of Accessible Travel, a specialist tour operator providing holidays for people with mobility impairments, and has huge experience in the travel trade.

**Money management:** David Clarke has spent 14 years in banking and has worked for three leading financial service providers. He is now a senior partner with Clydesdale Bank and his wealth of experience is all yours.

#### Access & the Environment:

**Agnes Fletcher** is a disability trainer and consultant who can find solutions to access problems.

**Property:** Kate Sheehan is an independent occupational therapist with 20 years' experience and a

passionate interest in housing solutions for disabled people.

**Motoring & Transport:** Helen Smith of

Mobilise steps outside her Disability Now column to answer your questions on car matters.

# pete's place

## Hurry along slowly on social care



As the Government at last launches its green paper with proposals on fixing the care system, **Peter White** says it's been too long coming

It would be interesting to know how governments define the word urgent. Judging from experience, it only has one true criterion – something that might lose them an election! Eighteen months ago, *You and Yours* on Radio 4 ran a whole season of features pointing out the extreme urgency of reforming Britain's social care system.

Eighteen months before that, Sir Derek Wanless produced a report for the

health think-tank the King's Fund, which pointed out that our social care system was broke (in both senses of the word), and urgently needed fixing. He proposed some kind of system based on partnership, funding from both the individual and the state and a recognition that social care should be a universal entitlement, not something which local councils funded if they happened to have enough money left over. In other

words, a system which looked much more like the health service.

Even Wanless can hardly claim to have been a revolutionary. Demographers have been warning us since the 1960s that we had a problem, based on the inevitability that as people lived longer, we'd have a chronic imbalance between those who could work to support those who couldn't. But did we do anything about it, as the oil revenues rolled

in, and cats got fatter by the minute? No, we didn't! We waited for meltdown.

The problem for disabled people is that the system designed to help us, is the same one that's supposed to carry the weight of the demographic time bomb, and clearly, it can't. So has the current Government cottoned on to the fact that this is an urgent problem? Well, it says it has; successive social care ministers trooped into our studios to say they had. Even the prime minister said he had.

And the response to this "urgent" problem – a green paper, which has taken another 18 months to produce, and so far as I can see, marches us yet again through the possible options; those very same options that Wanless, *You and Yours*, and various other social thinkers, have already set out.

And even now that we have a green paper, we're going to have another 16 weeks of consultation, followed by a white paper, when we might finally find out what the Government proposes to do about it. By which time, of course, they could afford to be deliciously radical, since it seems unlikely that they will be required to provide delivery. That'll be the new lot.

### ed cetera

Ruth was very pleased with the way her personalised care package was shaping up.



EdsArt

# guest column

## Life and death - choices and rights

Lord Falconer's amendment to the assisted suicide bill failed to make it to the statute book. Some say it would have clarified the position of relatives who help family members to die, **Margot Milne** unpicks the complexities

**O**ne hundred and fifteen Britons have ended their lives at the Swiss suicide clinic Dignitas since 2002. Eighty had cancer, MND or MS. The rest had conditions normally considered non-terminal, including rheumatoid arthritis and tetraplegia.

Some commentators have expressed horror that people with non-terminal conditions should seek assisted suicide. And of course we all know that disabled people can lead meaningful and empowered lives. So why would a non-terminally ill disabled person take the apparently extreme step of travelling abroad to seek help dying?

I'm in the final year of a PhD, researching disabled people's attitudes to issues like assisted suicide. I also have MS. I've gathered opinions from people with a range of impairments.

Some people want to keep living, without question. For others, it may be the fact that the condition isn't terminal that makes them want to end their lives. They find their



REX FEATURES

situation unbearable, and do not want it to continue indefinitely.

There's a particular dilemma for people with progressive conditions who may want to take their lives later. Do they kill themselves now, when they don't want to die but are still physically able to do so? Or do they wait until they feel the "right" time has come, by which time they're no longer able to do the deed? I believe that this is why some people with progressive, non-terminal conditions seek out clinics like Dignitas.

Debbie Purdy (*pictured*), who has MS, has been

seeking legal clarification. Helping someone to travel to a clinic could be interpreted as assisting them to commit suicide – which is illegal in the UK.

Purdy asked for a ruling as to whether her husband would be prosecuted for helping her to travel abroad for assisted suicide, if she should choose that in the future. But the courts say it is up to Parliament to change the law.

An amendment to the

assisted suicide bill said that any help to travel to a country where assisted suicide is legal will not be treated as assisting suicide, as long as: two doctors confirmed that the person was terminally ill, the person made a formal declaration before a witness who won't benefit from their death that they understand they're terminally ill, and plan to seek assisted suicide in a country where that is legal.

Some thought this went too far – attempting to legalise euthanasia here by stealth. Others that it didn't go far enough, being limited to people who are terminally ill. As someone with a progressive condition, I believe that this amendment would have given those very few people who do wish to travel to clinics like Dignitas the assurance that their loved ones would not be prosecuted as a result of helping them.

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# upclose & personal

## Loving care, caring love

The phrase "disabled carer" risks eliciting gushing and inappropriate responses. But for **Alan Sutherland** and his partner, care in every sense is just part of life



I met my partner Victoria through the Campaign for Accessible Transport. We spent many happy hours together reducing London's West End to gridlock with sit-down demonstrations demanding access to buses. We annoyed a lot of motorists, but wheelchair-users can now catch the bus into town.

Back then in 1990 Victoria walked with a stick, though it seemed obvious to me that she would benefit from occasional use of a wheelchair – an issue that resolved itself as soon as she realised how much easier a wheelchair made clothes-shopping trips.

Like many disabled

**The woman I love sleeps on her own in a hospital bed. It was only when we shared a bed together again on holiday that I realised quite how much tenderness this had robbed us of**

couples, we supported each other's access needs. There was one appalling month where a new medication lost control of my epilepsy. I was having two major fits a day. I don't remember much of that time. But I do remember that there was someone looking after me

for the whole of that period.

Since then, things have gone the other way. My fits are now entirely under control, while Victoria's MS has continued to advance. Imperceptibly, the balance of dependency has changed, and I find myself my partner's carer.

That doesn't mean I dress her or wipe her bum or put new dressings on her pressure sores. Mostly, that's done by agency care workers and district nurses, except when we go away on holiday or have a crisis in the middle of the night. This means that we can have a physical relationship that isn't dominated by incontinence but does bring

a constant procession of passive-aggressive women through our home. For them it's a workplace, and the only relationship of any importance in it is the care relationship.

So, for example, the woman I love sleeps on her own in a hospital bed. It was only when we shared a bed together again on holiday that I realised quite how much tenderness this had robbed us of. But when I have talked about getting rid of the thing, nurses and carers have threatened to withdraw services. They need it to protect their backs from injury, they say. Protecting our relationship doesn't come into it.

It's at times like these that a good grounding in social model thinking is invaluable. Problems are solvable. Though assured by OTs and nurses that no such thing existed, I've sourced a height-adjustable double bed that actually looks like part of an elegant home and am currently redesigning the bedroom to fit our needs.

There's a subtle pressure from nurses and care workers for Victoria to be a good patient, meek and compliant and grateful for their attentions. But if I have anything to do with it, the stroppy, independent woman I fell in love with will stay as she is.

# Top model. Still missing

More than a year on, Kelly Knox tells **Lara Masters** that she's still battling for recognition despite winning *Britain's Missing Top Model*

know I'm hot! But I'd never considered being a model. I entered *Britain's Missing Top Model* (BMTM) because I thought it would be fun. It wasn't until the final that it clicked; I loved dressing up and being in front of the camera and I really wanted to be a model.

"When I won the show, I was signed to the Take Two model agency. With all the publicity from the show, it shouldn't have been difficult to sell me but I felt the agency didn't really care about the opportunity we had to push me, a disabled model, and really make a difference. A few months after the show, when things didn't take off, I had to go back to my full-time job in credit control.

When Take Two folded, it gave me an opportunity to find an agent who'd believe in me. Since joining Lethal Model Management in February I've had much more work but not nearly enough to leave my office job. The modelling jobs that I've got have mostly been people asking specifically for me and my disability: I played the part of a zombie who's bitten off their arm in an internet commercial for Samsung, and did a fashion shoot in Germany with a designer who's an amputee. I also did a shoot for an LA-based jewellery designer who liked my look and didn't know I had a disability.

When she found out she referred to me as a "breath of fresh air" in the industry.

It's frustrating that I've been unable to model full-time and that the fashion industry struggles to see disability as sellable, but it makes me more determined to pursue my real passion to be a role model. With the modelling I can only do so much. I can't spread the word about equality and positivity just through people looking at a photo.

I've always been very confident and outgoing. Being born with one arm didn't make me shy and I never "hid" my arm from the world. Perhaps naively, I assumed that everyone felt like I did and accepted their own and other people's differences but I discovered that there are many disabled people who are negatively affected by their disability.

I got messages from viewers saying how much I'd inspired them to be more confident and it opened up my eyes to how important it is to have disabled role models in the media.

But I'm aware that being a role model comes with responsibilities and when I saw footage of me drunk and misbehaving on the programme, it rang alarm bells. Someone close to me is an alcoholic, so I know how destructive alcohol can be. I still go out partying and dancing but I don't



Assisting in evolution: Lara Masters (left) and Kelly Knox

drink at all now.

I was asked to give a talk at REACH (The Association for Children with Hand or Arm Deficiency) and I could see that some of the children were insecure and shy and I just wanted to drag that shyness out of them. I gave them practical advice like how I tied my shoelaces and I talked about my child-

arm and skipped. The speech went down so well I got a standing ovation.

Recently I did some artwork for Action for Children along with celebrities like Joanna Lumley and Gemma Atkinson. I drew a picture of myself with my eyes closed (before BMTM) and another of me with my eyes open (after BMTM). My eyes are now as wide as wide can be and I know what my purpose is.

I don't call myself "disabled" because I don't like the divide that labels cause. Equality should be a natural way of life and I hope that one day it will be. I want to help that process and be a pioneer for humanity! Hopefully in the near future, I'll be able to give up my office job and work solely to help make society more accepting for us all and assist humanity in its evolutionary process.

## Being a role model comes with responsibilities and when I saw footage of me drunk and misbehaving, it rang alarm bells

hood. Having one hand didn't stop me from doing anything; by the time I was five I could ride a bike without stabilisers and when I wanted to skip I cut off one end of the skipping rope and tied it round my



# Heading South to Middle Earth

**Paddy Masefield followed in the steps of Captain Cook**

New Zealand provided the stunning locations for Peter Jackson's Movie trilogy, *Lord of the Rings*, boasts the longest place name in the world and is home to 40 million sheep

**M**y argument to my wife was that if we were travelling literally to the other side of the world (I'd been booked as a speaker and workshop leader at "Momentum '09", New Zealand's prestigious Auckland Disability Arts Festival), we couldn't possibly return without having explored New Zealand's South Island. I'd heard that the scenery was dramatic and the action dangerous. Besides, it was the nearest we were ever going to get to Antarctica! So we packed thermal underwear, a sensible wheelchair and doubled my medical insurance. Sadly Momentum'09 fell victim to the Credit Crunch three days after we'd paid up front for our holidays. And you know what? I don't regret a penny of it!

If you are planning to visit New Zealand

it's best to get your head into tumbling calculator mode as these Islands (physically larger than Japan or the UK), throw up a mass of extraordinary facts and figures. First of all, topographically it's the world's youngest landmass, having only begun to emerge from the Pacific Ocean 23 million years ago. Next it was the last to be populated, around 1,000 years ago by the Polynesians – the Southern Hemisphere's equivalent of the northern Vikings. The British claimed it as colonial property by the Treaty of Waitaki in 1840. Then sent for droves of missionaries to stop the inter-clan Maori warring. So to find this was the first country ever to give women the vote in 1895 shook up my perceptions. After all, today it only has a population of four million compared to a sheep force of 40 million.

We flew into Auckland airport, gateway to a dozen internal airports, and home to more than a third of New Zealand's entire population, who also have a higher sailing boat ratio per capita than any other port. So we transferred straight onto a flight to

## Did you know?

The place with the longest name in common usage is a 252 metre high hill in Central Hawke's Bay, New Zealand. Taumatawhakatangihangakoauauotamateaturipukapikimaungahoronukupokaiwhenuakitanatahu translates as the 'place where Tamatea, the man with the big knees, who slid, climbed and swallowed mountains, known as land-eater, played his flute to his loved one'.

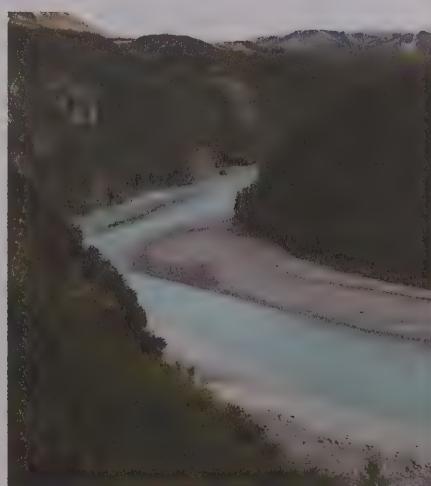
Christchurch, the largest city in South Island. Usually described as more English than Oxford – you can even punt on its River Avon – though it was currently heavily polluted. And on a Sunday afternoon its neat squares around the Cathedral with statues of Queen Victoria were packed with Scottish pipe bands blowing away pre-competition cobwebs, on a diet of fish and chips.

Also on a diet of fish, as well as four metre long squid, were the pod of six bachelor sperm whales resident a mere mile or two off the old whaling town of Kaikoura, three scenic hours drive north of Christchurch. Elsewhere in the Pacific you have to hope for an occasional glimpse of migratory pregnant whales, searching for warmer waters during the UK's summer months, on account of their thinner layers of blubber. The Sperm whale has the largest head and brain of any animal. Up to 50 tons in weight it can remain submerged for over two hours and dive up to 3 kms deep – all made possible by the extremely rare coincidence of a 3 kms deep trench (the Hikorangi) in the ocean floor so close to land. We see five whales inhaling air on the surface, before it's "flukes up" for the photographer, a large group of dusky dolphins play boisterously around our boat, fur seals spread themselves on the rocks below a local winery and the world's largest bird, the albatross, gives us a fly-past. I'm in seventh heaven, adoring all things maritime.

In fact the earliest white settlers in New Zealand believed they had found the Garden of Eden, so bountiful was its soil and so breathtaking its landscape. We put this to the test next day by taking the TranzAlpine train from East Coast to West Coast. This entails crossing the Southern Alps, the result of a tectonic plate crunch so



**Top to bottom: Paddy and Caroline were here; a river bed scoured out by a past glacier; the Fox glacier**



long it can be seen from space. Eighty per cent of South Island is covered in mountains, with the narrow plains of the East Coast pouring out such rich dairy produce that before the UK joined the EU, its guaranteed imports made New Zealand one of the richest countries worldwide. Also in search of wealth were the 5,000 gold prospectors who blazed the trail for the train tracks in the 1860s. It's rated one of the world's most beautiful rides, and for me the wealth of New Zealand lies in the spectacular transitions from plains to canyons hundreds of feet below us that wait to be flushed with melt water from the surrounding snow capped peaks every spring and draining out of high mountain lakes. Without warning this landscape transforms into almost prehistoric beech forests, floored with New Zealand ferns, as we reach Greymouth bordering the Tasman Sea.

Here we hire a car. This independence and slower pace has to be the best part of the journey southward. We're on National Route 6 but only see another car every five minutes. Even towns marked on my ➔

## Did you know?

Traffic calmers in Kaikoura are known not as sleeping policemen, but as sperm whales. (Because at sea they float on the surface with only a fraction of their body mass above the water).

road map can consist of a single farm and an improbable school; while every 50-house settlement has its own golf-course and race-horse track. I presume the numerous rugby grounds are legally compulsory! It feels like a countryside still waiting to be discovered. The flora and human fauna are equally healthy. We pass serious hikers, surfers, frivolous 1960s hippy camper vans and back pack cyclists on tandems. Our destination is Franz Josef township, a mere 270 inhabitants and a one industry service town. Here they fly helicopters for non-walkers such as myself and we fly around Mount Cook, the Island's highest peak, and then land on snow, ice-hardened by the sunlight. (Our warm winter wear is totally unnecessary as South Island has a temperate climate and we're in the warmth of the first official day of autumn.) We're also in one of three UNESCO world heritage sites on the Island. I've never seen a glacier before and am awed by Fox Glacier's ability to throw up great ice blocks and crevasses on its 13 mile steep descent to the coast – being one of only three glaciers globally to end among lush rainforest a mere 200 metres above sea level – sadly Fox's Glacier Mints were not named in its honour; but its dangers were underlined by the deaths of two Australian tourists a month before we visited. South Island has 367 surviving glaciers and amazingly those on the west coast are growing at a rate of a metre a year!



Top: 'The Pride of Milford Sound'; bottom: The Tranzalpine Railway



We drive further south. The road forces us to turn inland, and we circumnavigate three sides of a remote mountain area guarded by broad lakes, tumbling waterfalls and boulder strewn river beds carved out by earlier glaciers. This is the remote quarter where the dramatic scenes from *Lord of the Rings* were filmed. We drive past six ski resorts awaiting the winter snows and look down onto the awesome valley

that is Queenstown – the self-styled "Adventure Capital of the World". Here, at the world home of bungee jumping, you can Jag Air fly upside down, embrace the fear of tandem skydiving, endure the heart-stopping momentum of the Shotover River Jet as it navigates the shallow braided channels (in sometimes as little as 5 cms of water, but at 85 kms per hour), or simply white water raft through the



The Hobbits' houses were filmed on North Island. The rest of *The Lord of the Rings* on South Island.

total darkness of canyon tunnels.

We opt for a three hour coach drive! Passing South Island's largest lake – Te Anau – and the Remarkable Mountains (it's their name, honestly). We're headed for Milford Sound. A fjord declared by Rudyard Kipling to be the eighth Wonder of the World. To reach it we travel on one of the five most avalanche prone public highways in the world and through the Homer road tunnel, only built long after New Zealander Sir Edmund Hillary had stood atop the summit of Mount Everest. We transfer to a vessel named The Pride of Milford Sound and head seawards. The scenery is fjordly stunning (though I suspect Kipling had never experienced Norway's somewhat longer and deeper fjords). On disembarking we're booked on one final helicopter return flight to Queenstown. Wow! This pilot's watched too many Vietnam films. We're slammed up against granite faces where surely the blades must strike rock; then dramatically fall 500 metres into a ravine, before soaring up above the snowline for one last open air glacier experience. It's fine unless you're sat

upfront with only a thin perspex bowl between your shoes and certain death. Only later do I learn that when not transporting tourists, these pilots become New Zealand's "Cowboys of the Sky" firing nets over mountain deer to swing them down to the plains to add to the 3.5 million already being farmed.

*Disability Now* readers are used to images of wheelchair skiers and blind British drivers setting world records on motor racing tracks. Nonetheless, South Island would have remained inaccessible to me had it not been for Burt Bacharach's "Trains and Boats and Planes" – plus some pleasantly accessible hotels, and an ethos of ever-improving disability equality. Our best coach driver/tour guide was both Maori and a disabled person. So please, despite all the implications of a massive carbon flight footprint, don't leave your travelling too late, until you're too old to enjoy and learn from the experience. Travel provides such an amazing sense of ownership of our world. That's ownership as in responsibility for the whole world of which we're citizens, and not just our own irritating little patch called home. And I offer you one last fact. Disabled people now amount to one third of the global population. So take a look at what one day we're going to take over. ■

• A single return flight to Auckland currently costs around £750

### Did you know?

Sperm whales' poo used to be regularly used in the manufacture of perfume.



Top to bottom: ten sheep to every one inhabitant; fur seals basking in Milford Sound; a Kea – a South Island mountain parrot



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*Top: Libby; top right: Sophie; middle far right: Elena and centre: Hassan*



## Getting in the swing

Summer's here and the time is right for heading to the park. **Sunil Peck** checks out a new bit of kit for kids for whom a trip to the local swings isn't an option

The Liberty Swing is ideal, says its designer, for young disabled people who cannot sit safely on a conventional swing.

It accommodates wheelchairs, but has a seat that can be flipped down if needed, too.

I visited the playground at Waverley School in Enfield one lunchtime to see how much fun the students there have on the swing.

Hassan gave me a cheery

wave, Sophie laughed throughout her ride, and Libby high fived her support teacher as she swung. Elena was unsure about the swing at first, but soon decided she liked it.

Louise Gibbs, the headteacher at Waverley School, says that the swing is popular and that students aged between 5 and 19 queue to use it at playtime.

"A lot of our students have very limited

purposeful movement because of their physical disabilities. The swing gives them movement that they can experience without being held by somebody."

At more than £12,000 to buy and fit, the Liberty Swing will be too expensive for most families. But it is already a playground favourite and it could be installed in parks for disabled people and their families to play on too.



### INFORMATION

Geoff Daly, Liberty Swing (UK) Ltd, PO Box 3953, Windsor, Berks SL4 9AP

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[www.libertyswing.com.au](http://www.libertyswing.com.au)

Last November I wrote about the growing trend by councils to develop their town centres as "shared surfaces". The plan is that these will reduce the dominance of vehicles and make them more people-friendly.

So far the main view coming from the disability sector is that this type of street design is detrimental to the confidence and independence of disabled people, especially those who are blind and partially sighted. This is because disabled people find it harder to get out of the way of traffic and guide-dog owners and cane users need a kerb to navigate. But is this the only viewpoint coming from disabled people?

The charity Guide Dogs have been instrumental in leading a campaign against the shared surface scheme on Exhibition Road in Kensington, west London. Guide Dogs spokesman David Cowdrey said: "They want a single surface at any cost. The whole point of the design is that you make eye contact [with drivers]. If you have learning difficulties or are visually impaired you'll have difficulty."

But not all visually impaired people are against shared surfaces. Nominated

## Share options on the street



As more councils around the country consider putting vehicles and pedestrians together, **Helen Smith** asks whether there are any arguments in favour for disabled people



**QUALITY STREETS:** Disabled people's demo at London's City Hall against shared surfaces

Access Champion of the Exhibition Road scheme is Cllr Andrew Lamont. He says "Guide Dogs are

caught up with the idea of shared surfaces, but it's a single surface, not shared between traffic and people.

We've got to have fairness for all disability groups. As a visually impaired person I know it will be fabulous."

Currently Cllr Lamont's view is pretty unique amongst disabled people. The Disabled Persons Transport Advisory Committee (DPTAC) have raised serious concerns about this type of street design and Arthritis Care have also stated that they think people with arthritis would feel more vulnerable surrounded by cycles and vehicles moving at high speed.

As a mobility impaired person I share the concern raised by Arthritis Care that I would feel vulnerable with bikes whizzing past me but my greatest concern is how quickly and easily I could move out of the path of a moving bus. If I was using a wheelchair I would also be concerned that drivers would not be able to see me. However, a shared surface scheme which allowed me to drive my car down it and park close to where I needed to shop would allow me far more access than a pedestrianised scheme where all vehicles are banned. For me being able to park close to my destination is the most important thing.

With so many concerns regarding shared surfaces



GUIDE DOGS

The Department for Transport has commissioned a consultancy company to carry out some research.

The aim of the research will be to try and define some design guidance to highway authorities and others

## My greatest concern is how quickly and easily I could move out of the path of a moving bus

developing shared surface schemes. I recently attended one of the sounding board meetings and was interested to learn that research has shown that shared surfaces can be good for Blue Badge holders as they can park in the zones. There is also no evidence that these

schemes increase or decrease casualty rates but one report did show that shared surface schemes have more conflicts, but of lower severity and less likely to result in injury. This research project will run until February 2011 leaving plenty more time for discussion.

However, with more towns and cities planning these schemes guidance is urgently required to ensure that street design doesn't impede disabled people from enjoying their towns and cities.

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# Double Dutch at Wimbledon

Dutch duo Korie Homan and Esther Vergeer made history at the All England Tennis Club, winning the inaugural women's wheelchair doubles title at the Wimbledon Championships.

The top seeds saw off British tennis star Lucy Shuker and her partner, Australian Daniela di Toro 6-1, 6-3, ending Shuker's hopes of becoming the second Briton after Jayant Mistry to win a Wimbledon wheelchair doubles title.

Speaking ahead of the Wimbledon final, Shuker said: "Ever since I started playing wheelchair tennis in 2003 it's been a dream to play at Wimbledon, so now that I'm here we were determined to make the most of it.

"For us to reach our first Grand Slam final together is fantastic. We'll go away now and talk to our coaches and try to come up with a plan to try and beat Korie and Esther in Sunday's final. It's obviously going to be tough, but we will do our best and will enjoy it."

However, after winning their semi-final 6-0, 6-0, Homan and Vergeer always looked the favourites to



claim the inaugural title, and went on to make it seven successive tournaments without losing a single set.

"We knew it was going to be tough, they are the world's top ranked players, but we did our best out there and took it to them in the second set, but they were just too good," said Shuker.

"There is some disappointment, but to get to the final was a great achievement and to play at Wimbledon for

the first time has been incredible.

"I look forward to hopefully having another chance again next year".

"It's amazing to win this," said Vergeer. "I watched Wimbledon at home all my life and just to be here in the grounds the other day gave me goose bumps, so to get playing was a great feeling. Of course you think about winning, but to actually do it is another thing and to win the inaugural Wimbledon Women's Wheelchair

Doubles title is another great thing I can add to my list," she said.

The top seeds also prevailed in the men's wheelchair doubles, with French duo Stephane Houdet and Michael Jeremiasz seeing off Robin Ammerlaan of the Netherlands and Shingo Kunieda of Japan with a 1-6, 6-4, 7-6 victory in a nail-biting final.

Homan and Vergeer and Houdet and Jeremiasz now go on to lead the Dutch women's and French men's teams in the 25th Anniversary World Team Cup, the Davis and Fed Cups of wheelchair tennis, at the City of Nottingham Tennis Centre from 27 July to 2 August.

Meanwhile, two-time Paralympic champion Peter Norfolk heads a Great Britain squad of 13 players that will contest each of the men's, women's, quad and junior events.

Norfolk, his Beijing quad doubles bronze medal-winning partner Jamie Burdekin and Andrew Lapthorne will start among the favourites to try and earn Great Britain a third Invacare World Team Cup quad title since 2001.

## Danny Crates quits

Former Paralympic gold medallist Danny Crates has announced he is to retire from athletics.

Crates, who was Great Britain's flag bearer at the 2008 Games before a calf injury ruled him out of competing, will run in one final race at Crystal Palace on 25 July.

The 36-year-old had struggled with injuries in the past 18 months, and saw his comeback on the world stage at May's Paralympic World Cup end

in disappointment as the recurrence of a hamstring injury forced him to pull out of the T46 800m with just 200m left to run.

He said: "The last two years have been tough for me. I had the massive high of carrying the flag in Beijing, followed closely by the massive low of not being able to compete. In the lead up to the Paralympic World Cup in Manchester, I had a hamstring injury and I probably made a comeback to racing a week too early.

"It was very disappointing

and was the first time I've not finished a race in ten years.

"The mind is willing, but I'm not sure that the body is anymore. I am going through a stage that every sports-person has to face up to at some point. London 2012 would be a long shot for a 39-year-old athlete and there isn't another international championship open to me for another 18 months."

Crates added that he has always been "hugely honoured" to compete for Great Britain.

"It means the world to me, I have had 11 years as

an international athlete and it is not going to be easy to walk away."

On his final race, he said: "Ever since I began to think about retirement, I have always wanted to do it at Crystal Palace. As an athlete you get to travel and compete all over the world, but the true excitement comes in front of a home crowd. I know it will be very emotional with my family and friends present, but I cannot think of a better way of saying thank you to all those who have supported me over the years."



# Liberty

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# Glasto

## Mud, Blur and bags of attitude

**Cathy Reay** and **Paul Carter** high-fived when they heard their next assignment involved hangin' at Glastonbury 09. Then they heard that there would be a stage of disabled bands on one of the festival days, and hearts sank. Was this going to be some pitying "look at us – we're special" show, or would people actually realise the musicians' talent and forget that they might look a little different

**G**lastonbury is renowned for being the biggest contemporary arts and music festival in Europe. With over 200,000 attendees at Worthy Farm, just outside the small village of Pilton in Somerset, its huge sprawling mass is daunting to anyone, particularly people with mobility difficulties, like myself and my colleague Paul Carter.

To begin with we were naively optimistic about the amount of expected mud. The opening night saw huge showers and thunderstorms directly over the site, ensuring that by midday Friday, swamps had formed trailing the length of every necessary route to and from each stage.

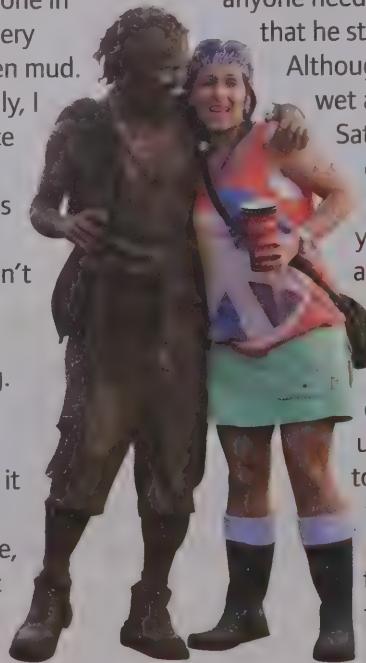
For someone as uncoordinated as me, this was very bad news, particularly because I find it difficult to balance on level ground let alone in gloopy, slippery sticky, uneven mud. Unsurprisingly, I fell over twice and missed several bands because I simply couldn't access the stages they were playing. Neil Young more than made up for it though with his incredible, atmospheric headline set on the

Pyramid stage. Playing old and newer tracks both acoustically and with his full band, Young's exhaustive two-hour set proved, in case anyone needed reminding, that he still has it.

Although Friday was wet and miserable, Saturday was one of the hottest days of the year so far and as a consequence the ground quickly dried out. It enabled us to head down to the Shangri La fields, at the opposite end of the site, to see the disabled bands on the

Club Dada stage, run by Attitude Is Everything.

After consulting our poorly-scaled map, we estimated that it would take us over an hour to walk to the fields. Given that we were exhausted from the previous day, we decided to enquire about alternative forms of transport. Waiting over 40 minutes, we were then told that buses were available from the disabled camping area to three of the stages, not including Club Dada. We took one bus, which got us a little closer, but still had to walk quite far at the other end on incredibly uneven ground. When we wanted to leave we had to wait a staggering two hours for a bus back to the main site.





PHOTOGRAPH BY CATHY REAY

The Shangri La field turned out to be the hippiest and most happening place to be. Families seemed to have decamped here to escape the mainstream masses and chill out with circus, jazz and cabaret acts. It's such a shame it's very hidden away from everything else, but perhaps if it wasn't it would be just as congested as the main area.

Club Dada got off to a slow start with electro-rock outfit Spaceships Are Cool. Fronted by Rob Madisson, who is in a wheelchair, when describing their sound he said that they "try to incorporate sci-fi sounds of the 60s and 70s into modern music". One of the instruments they use isn't even tangible; it's a magnetic field which sound is

generated from when you move your hand within it. The crowd got bigger and better through the set as strays wandered in from outside.

Speaking to us afterwards, Rob said that, because he was nervous about playing again as a recently disabled person, coming to Glastonbury with Club Attitude created a very "safe environment" for his band. "I think this is a great way to promote the issue Club Attitude are raising [of accessibility at festivals and venues], and a chance for us to say thank you to them for helping us."

He agreed that he'd like to see disabled musicians playing on the larger stages too, but said that he didn't think they would purposely turn disabled musicians down; just there was no opportunity for it this year.

While there we also spoke to Grae Wall, Attitude is Everything/Club Attitude's promoter. "The long-term aim is that we work towards a world where venues and festivals automatically think about being accessible from day one. The short-term aim is that the bands we put on today have been given an opportunity to perform at this huge festival," he told us.

"We don't want these musicians to be noticed for the fact that they've got a disability but for the fact that they're just really



Spaceships Are Cool rock the Club Dada stage



Impromptu gigs in the Shangri-la fields



good musicians."

Surely putting them on a bill of disabled musicians and promoting it as such is invoking an unnecessary separation between the two, though?

"We do tend to try and



mix it up, no-one in the final band playing in our line-up has a disability. We had this limited window of opportunity so I had to ask myself whether to offer it to bands we regularly try to support and might not get →

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the chance to perform here if it wasn't for us, or to utilise it to be more of a mixed forum. The last thing we want to do is create another ghetto," he said.

Next up on the Club Dada stage was Al Cool and the Stranger Wines, who sound very much like Manu Chao. Cool hippie beats with an indie twang, we liked them a lot, and the tent was packed for their set.

After our two hour wait for a bus, we returned to the main site to watch Crosby Stills and Nash (who sounded a little wrong without Neil Young), indie darling Florence and the Machine (who has a very cool look and style, but rather unoriginally composed songs) and the evening's headliner, Bruce Springsteen. We'd been looking forward to Springsteen for a while but sadly his two and a half hour slot didn't match expectations, largely because he didn't play a song anyone recognised for the first half of it.

The good weather held up on Sunday, with just a light spot of rain and cloud bothering the sun. The performances during the day were rather eclipsed by the impending reunion headline slot by Blur. They definitely didn't disappoint; bounding through a two hour set jam-packed with hits (even we, as hardcore fans, didn't



**Top: Paul Carter. Bottom: Cathy (right) and her friend**

realise they had so many), they moved through their own music in a timeless and classic way, in a way only the members of Blur know how to do. And the 150,000 strong crowd really loved it.

We trundled off to bed, knackered but happy. Though my colleague stayed in a tent on site (which he had to do on his own as our friends were camping too far away for him to join them), I had booked a lovely B&B for the weekend. The only trouble was, it was a huge pain to get to, and involved several expensive taxis in the middle of the night. On that almost fateful Sunday evening I was told to get on a bus, which would apparently take me back to my accommodation, but I ended up in Cheddar.

Fortunately for me, a fellow festival goer was prepared to drive me the hour and a half back. Let that be a lesson learned: if and when getting accommodation, make sure it's very near to the festival site or that transport links are easy. There is nothing much worse than standing alone in the middle of a deserted village at 3am.

Overall, Glastonbury presented both expected and unexpected revelations, in terms of accessibility, attitude towards disabled people and music talent on show. No-one can prepare for how massive the site is, or really avoid it, but it would have been a lot easier if we had been given easy access to transport links around the areas we wanted

to go. It also would have been a lot easier on the muddy Friday if I had remembered to bring wellies.

The work that Club Attitude and Attitude Is Everything are doing is fantastic; accessibility should be a given priority at venues and festivals, there's no reason why someone shouldn't be able to access music because of their disability and it definitely needs that recognition and hard work the organisation are putting in. However, for me personally I really don't like being segregated or made to feel "special" and, whether intentionally or not, I did feel that their Glastonbury event did this.

As one of the members of Al Cool and the Stranger Wines was telling me after their set, people shouldn't look at a band and consider a member's disability a negative thing when it comes to their success, otherwise it will be. These bands, who are just as talented if not more so than lots of the other acts playing Glastonbury, should be playing slots on larger stages between bands that have no disabled members. People shouldn't be made to feel like they should see them because they are "disadvantaged", they should be made to feel like they should see them because they are very good musicians. ■

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Sainey and Alie

Vicky, from Scope Response, recently visited a family, where their son, Alie, has cerebral palsy. They were living in a cramped council flat and couldn't cook because it aggravated Alie's lung condition.

Vicky helped the family get a re-assessment and within just two weeks the family was re-housed.

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# webwatch

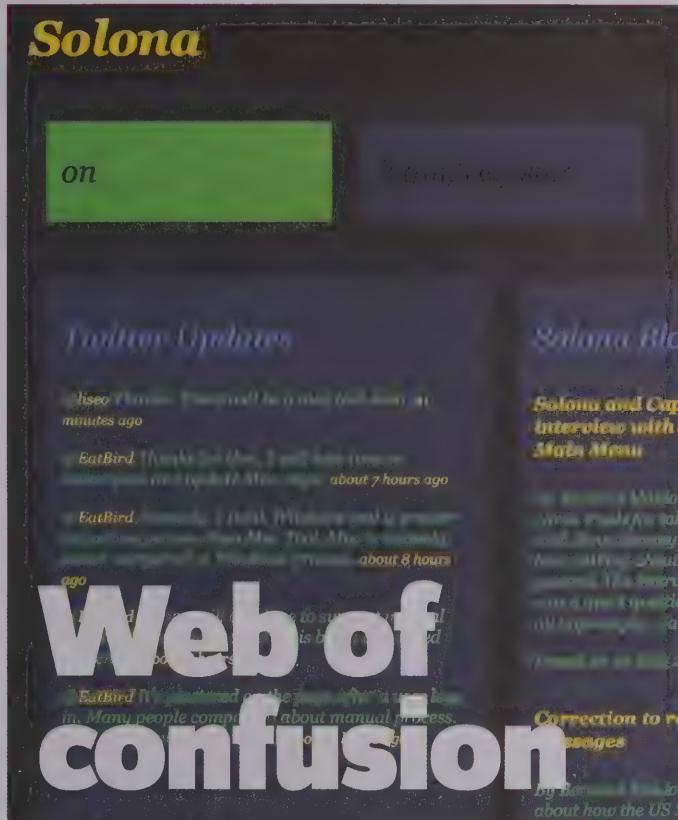
It may seem bizarre, the head of a team delivering consultancy on website accessibility and usability avoiding using the internet, but it's true – and it's not because it's too much like the day job. I avoid using the internet whenever I can because it's often just too frustrating and cumbersome.

That's not to say I don't use the internet: I use the darned thing every single day of my life (weekends too). I use it because it's essential for my work and indispensable for play. But ask me if I like using it and most of the time my answer will be a resounding "No!".

For me, as a blind surfer, in common with people with a range of other access needs and requirements, the internet offers a series of accessibility pitfalls that need circumnavigating and usability obstacles that need to be scaled.

Ten years on from the first publication of a set of globally-adopted accessibility guidelines (recently updated to include Web2.0 technologies and practices) and still most websites are littered with challenges.

There are, of course, many relatively accessible sites that are pleasant to use, but for each site that's usable there are ten that



It's coming to something when someone like **Robin Christopherson**, a consultant on web access, finds himself avoiding the internet because it fails to meet his own access requirements

are painful and laborious.

One way to avoid the internet is to use accessible desktop clients – navigable screen icons – as alternatives to a website wherever they exist.

One such is McTwit, the Twitter client (<http://mctwit.com>). Despite the Twitter website (<http://www.twitter.com>) being relatively accessible, desktop applications are usually

inherently more straightforward, more efficient and thus more enjoyable to use.

When searching for a bit of information or keeping abreast of news, I stick as far as possible to websites I know are usable. I won't use a site's search engine to

search a site: instead I'll use Google with the "site" prefix to limit the search to that site alone.

Similarly, I won't trawl news sites for headlines: I'll set up Google alerts to provide me with a digest of links to take me right to a news story page on a site. I've also subscribed to mailing lists and podcasts (and even read online blogs) to discover workarounds to some of the net's more intractable problems. CAPTCHA [tests on web forms that distinguish between computers and users] is useful. Were it not for the CAPTCHA solving services of WebVisum (<http://www.webvisum.com>) and Solona (<http://www.solona.net>), many blind users without assistance would have to avoid using websites that required registration.

The internet isn't going away, this I know. So come on web designers and developers – please think about all your users. Build to the guidelines, test with disabled users, and then I'll use your websites and web applications... if I have to!

## → Have your say

- write to us Disability Now, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)
- phone us 020 7619 7323

# Anything to declare... only my paranoia

Journalist **Richard Shrub** examines the thorny issues surrounding coming out about mental health conditions when you're in the job market

I was a lamb to the slaughter when looking for employment on graduating with an MA in broadcast journalism. I believed that the Disability Discrimination Act would prevent employers from discriminating against me. I learned the hard way that this was not the case. After flying the interview, and being verbally given a job offer, I mentioned in passing that I have paranoia. Three people grilled me for an hour about my psychiatric illness. The job offer was withdrawn and because they did not put it in writing, my lawyers said that it was their word against mine.

Cheltenham Borough Council was open about the fact that it would have broken disability discrimination law if they had known of Christine Laird's psychiatric history. Having proceeded to implement its decision to employ her, they sued her for almost £1 million because she had not



Christine Laird at The Royal Courts of Justice

Society, which generally only encounters schizophrenics like me in the media when we have battered our parents to death, is far from ready to allow us a productive place in it.

mentioned her depression on her pre-employment questionnaire. They lost.

This raises the question, whether it is right to lie about your psychiatric history on your pre-employment questionnaire? You'd have to be brave to mention your psychiatric illness in the face of statistics such as those revealed by mental health rights lobby Time to Change recently: apparently 60 per cent of us will face discrimination in the workplace. Society, which generally only encounters schizophrenics like me in the

media when we have battered our parents to death, is far from ready to allow us a productive place in it.

The Laird case raises an interesting point of law. It is illegal to lie on your pre-employment health questionnaire. However, it is then illegal for them to discriminate against you on the basis of your disability. In practice the mental health charity Rethink says that: "Those who do not disclose lose protection under the Disability Discrimination Act and can be fired if they are discovered to have withheld

this information. People are stuck between a rock and a hard place."

A similar position of power to Laird's was had by someone else with psychiatric history – in 10 Downing Street. In a recent BBC Two documentary, Alistair Campbell talked of how he was put under a police section when spending time with his friend, then Labour leader Neil Kinnock. He stayed friends with the Labour leadership because Kinnock's eventual successor Tony Blair recruited him, in full knowledge of his toxic psychosis, as Downing Street press secretary. He held the post for a decade.

Do we lie? The odds are still against you if you don't. But unless more people do tell the truth, will progress be made? If like me you have the gumption to tell the truth, and campaign when foiled, then we will all make progress.

**FOR SALE** - Tel: 020 7619 7336, Fax: 020 7619 7331,  
Minicom: 020 7619 7332, email: [patrick.durhammatthews@disabilitynow.org.uk](mailto:patrick.durhammatthews@disabilitynow.org.uk)

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Cont'd see pg 68

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## Darlington Association on Disability

Registered Charity No. 1125848

DAD is an organisation led by disabled people which exists to promote independence and choice through the provision of services, support and information.

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**Carer Support Worker (CSW)** up to £16500 per annum. To identify and support carers, provide relevant information, to lead on the personalisation agenda, and provide a voice for carers.

**Information and Advice Worker (IW)** up to £20895, to cover Maternity Leave to June 2010. To work in Darlington within its Equal Access to Information and Advice Project. The post is funded by the Big Lottery Fund to improve access for disabled people to Disability Rights information.

**Development Worker (DW)** up to £16950 to develop a p.a. register and support the development of user led groups and the promotion of the personalisation agenda in Darlington. (Part funded by Capacity Builders until March 2011)

The successful candidates must have an understanding of the Social Model of disability.

For an application pack telephone 01325 489999 or go to [www.darlingtondisability.org](http://www.darlingtondisability.org) and follow the links to the vacancies page. All applications are to be received no later than 14th August 2009.

Supported by  
**The National Lottery®**  
through the Big Lottery Fund



## CONFERENCE AND EXHIBITION



# techshare

## Digital technology conference for the disability sector:

- Learn about exciting new technology
- Network with others interested in digital assistive technology
- Meet leading industry figures
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- Meet the organisations developing the technology you use
- Hear directly from exhibitors in the "Bite-size Sessions"
- Meet other technology enthusiasts

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as an optional extra. Centrally located for beaches and tourist attractions. A peaceful location surrounded by woodland, not far from the A47 for easy access.

More details and prices, contact Rosemary on 01760 338797. Website: [www.narvalleycottages.co.uk](http://www.narvalleycottages.co.uk)

### DORDOGNE – SW FRANCE



Two stunning wheelchair accessible properties in the idyllic rural setting of Perigord Vert.

The Grande Maison sleeps up to 10, the Petite Maison up to 5. Contact **Ed Passant** on 01233 731097

or [ed@accessholidays.com](mailto:ed@accessholidays.com)

[www.accessholidays.com](http://www.accessholidays.com)

## Disabled & Carers English Coastal Holidays

All carefully designed for tetraplegic owner. Ceiling hoists Electric hi/lo profiling beds Shower/toileting chairs Pressure relief mattresses **LAKE DISTRICT: NEW!** Large caravan. Superb location and views. South-facing balcony Lake cruises, pubs, restaurants, many other attractions only 5-30 minutes away. Similar accommodation in prime location at **Filey, North Yorkshire Coast** Also apartments on level sea-front prom-path sea/mountain views sleeping 6+4 at **Heysham Morecambe Bay**. See [www.theukweb.com/disabledholidays](http://www.theukweb.com/disabledholidays) or call 01274 588142



### Cyprus - wheelchair friendly luxury private villa (max 12 adults), set in 2½ acres own grounds

Specifically designed this new luxury villa comprising of 6 double bedrooms (2 x ensuite), open plan formal dining room, lounge, kitchen (all mod cons), television lounge (Sky tv/CD systems), and outside living areas overlooking large swimming pool with steps for easy access (1.2m depth and child safety fencing), sunbathing area and outside B/Bque. Sited within 2 ½ acres of gated/fenced grounds the villa is ½ mile from the picturesque village of Skarinou, close to the motorway half way between Larnaca and Limmasol. Designed for an extended family/two families or small group to enjoy luxury living yet with room for privacy if required. Discount available upon request. For more inf please visit [www.exclusivevillacyprus.com](http://www.exclusivevillacyprus.com) or tel/fax Christine and David Williams on 0161 491 5910.

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Tel: 01833 628181 Fax: 01833 628020

Email: [mellwatersbarn@aol.com](mailto:mellwatersbarn@aol.com) Web: [www.mellwatersbarn.co.uk](http://www.mellwatersbarn.co.uk)



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dining room, kitchen, rear entrance lobby/utility area and cloakroom/w.c., first floor landing, four bedrooms (one of which has a dressing room and en suite shower room) and house bathroom/w.c. Outside, good size garden to the rear with parking to the front of the property and drive leading to lower ground floor garage and entrance. For details or to view the property call Richard Kendall, Estate Agent 01924 266555.

## HOLIDAYS

## Disabled Access Holidays



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[www.dah-europe.com](http://www.dah-europe.com)

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## DN DEADLINE

September 2009 published 1 September. Classified deadlines: Booking: 10 August. Copy: 12 August.

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# backlash



## I belong to Glasto!

Despite the mud, the blood, the scrapes and the stench, **Paul Carter** tells Michael Eavis, I'll be back!

**A**s you have already seen elsewhere in the pages of this fine publication, I recently had the privilege of spending five days living in utter filth with the great unwashed, or, to give it its proper title, attending the Glastonbury Festival of Contemporary Performing Arts.

Now, I know you all think you know what Glastonbury is like. After all, it gets such wall to wall media coverage that aside from the mud and the lingering aroma of a not too distant cesspit, you could actually forgive yourself for thinking you were there.

Let me put an end to that myth immediately. You have no idea what it's like. No idea at all. Until you have spent over an hour attempting to make a journey that should take ten minutes, through mud so slippery I'm surprised it hasn't been harvested as an industrial grade lubricant, then frankly my friends, you haven't lived.

I also broke my own record for sustaining a personal injury – precisely



CATHY REAY

three minutes after leaving my tent. I slipped and fell onto rubble and cut myself, attractively covering the ends of both my arms in blood, much to many people's horror. I think some of them saw the blood and thought for a second that my arms had actually just that second come off. I like to think so. Anyway, I digress.

I'm no physicist. But I'm fairly certain I've discovered something. I'm calling it the Glastonbury paradox. You see, in what was without a shadow of a doubt the most inhospitable, inaccessible environment for a disabled

person I could ever have imagined finding, the people suddenly became the most helpful, considerate and good natured I've ever met.

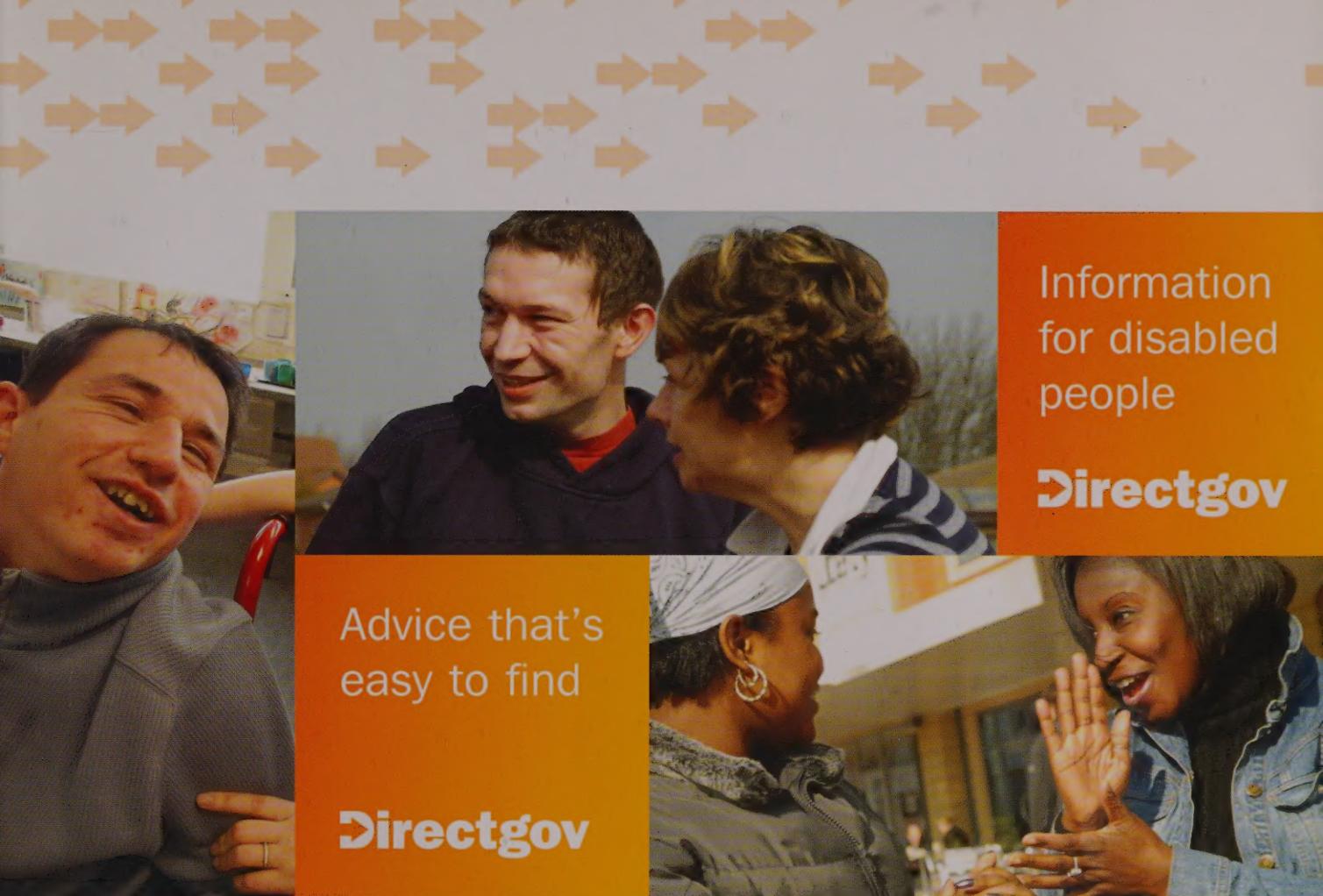
**“I think some of them saw the blood and thought for a second that my arms had actually just that second come off. I like to think so”**

Maybe that's what people are like outside of London in general, I don't know. At Glastonbury though, it was different. People camping

nearby helped put my tent up (ok so it wasn't so much "help" as "do the whole thing while I watch with a beer"), and during the aforementioned sludge trudge, complete strangers were practically dragging me through the mud. In a nice way (if there is a nice way to be dragged through mud) or lifting me over boggy trenches.

Admittedly a number of these people were more than likely "medicated", shall we say, but I don't care. Glastonbury Samaritans, in the extremely unlikely event that you remember dragging a bewildered, slightly overweight disabled man in a silly hat to the Pyramid stage, then I salute you.

So, what with the mud, the blood, the storms and traumas, you're probably thinking that I won't be going back next year. Aren't you? Well? Aren't you? Well you're wrong. Ha. It was brilliant, and I wouldn't have changed a thing. Apart from possibly the mud. 2010? You betcha. Glastonbury, I think I love you.



Information  
for disabled  
people

**Directgov**

Advice that's  
easy to find

**Directgov**

# **www.direct.gov.uk/disability**

Directgov is the website to visit for the latest information and services from government. It's clearly written, useful and the information is all in one place.

There's a large section for disabled people covering:

- ➡ home and housing
- ➡ financial support
- ➡ disability rights
- ➡ employment
- ➡ health and support

Find out about equipment, adapting your home or vehicle, direct payments (arranging your own care and services), social care assessments, the Blue Badge parking scheme – including an interactive UK-wide map, travel and transport, accessible technology – and much more.

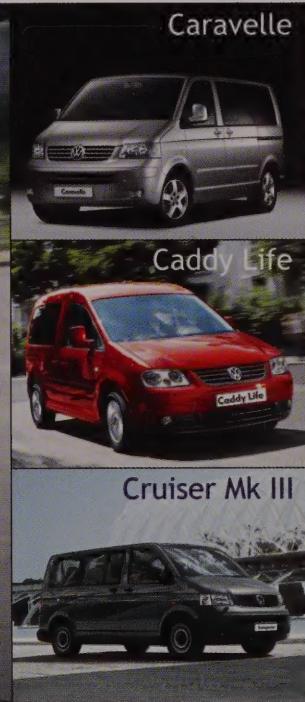
There's also information for carers and links to charities and helpful organisations supporting disabled people.

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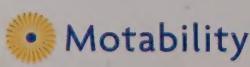
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